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# The (m)Health Connection: An Examination of the Promise of Mobile Phones for HIV/AIDS Intervention in Sub-Saharan Africa

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THE (M)HEALTH CONNECTION: AN EXAMINATION OF THE PROMISE OF  
MOBILE PHONES FOR HIV/AIDS INTERVENTION IN SUB-SAHARAN AFRICA

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by

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Graduate Program in Media Studies

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts

The School of Graduate and Postdoctoral Studies  
The University of Western Ontario  
London, Ontario, Canada

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THE UNIVERSITY OF WESTERN ONTARIO  
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**The (m)Health Connection: An Examination of the Promise of Mobile  
Phones for HIV/AIDS Intervention in Sub-Saharan Africa**

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## ABSTRACT

This thesis offers an examination of the complex opportunities and challenges that characterize the development of innovative, locally appropriate, sustainable, and scalable uses of mobile phones as instruments to support and advance HIV/AIDS work in sub-Saharan Africa. Drawing together the fields of ICT4D and health communication, this thesis establishes a theoretical framework for mobile health (mHealth) interventions in developing countries from a critical media studies perspective. It interrogates the varied applications of mobile phones vis-à-vis health that have been identified, promoted, or piloted in sub-Saharan Africa and elsewhere in the Global South, focusing on the potential for mobile phones to enhance two interrelated aspects of HIV/AIDS work: 1) scaling-up prevention and awareness programs; and 2) enhancing access to treatment, care, and support for people living with HIV. By critically examining real-life applications, focusing in particular on a case study from South Africa (the pioneering mHealth organization Cell-Life), this thesis explores both the opportunities presented by the increasing ubiquity of mobile phones in this region, and the corresponding challenges, limitations, and critical issues that inhibit effective realization of mHealth's potential in this context.

**Keywords:** mHealth, mobile health, HIV, AIDS, intervention, sub-Saharan Africa, mobile phones, ICTs, development, ICT4D, health communication, Cell-Life, South Africa, behaviour change communication, social change, text messaging, SMS, Mxit, developing countries, eHealth

We risk a failure of words, of concepts, of sympathetic insight in the face of AIDS. We need to fight this failure. We need to respond with imagination and compassion to what is happening around us.

Justice Edwin Cameron, “Human Rights, Racism and AIDS”

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## **LIST OF ABBREVIATIONS**

ABC	abstain, be faithful, condomize/condom use
ACT UP	AIDS Coalition to Unleash Power
AIDS	Acquired Immunodeficiency Syndrome
ARRM	AIDS risk reduction model
ART	antiretroviral therapy
ARVs	antiretrovirals
BCC	behaviour change communication
CDC	Centers for Disease Control and Prevention (United States)
CHW	community health worker
CITC	client-initiated testing and counselling
DOI	diffusion of innovations
DOT	directly observed treatment
GBV	gender-based violence
GIPA	greater involvement of people living with HIV
GPRS	general packet radio service
HAART	highly active antiretroviral therapy
HBM	health belief model
HCT	HIV counselling and testing
HIV	Human Immunodeficiency Virus
ICTs	information and communication technologies
ICT4D	information and communication technology for development
IDRC	International Development Research Centre (Canada)

IEC	information, education, and communication
IHC	interactive health communication
ITU	International Telecommunication Union
MDG	Millennium Development Goal
MDOT	mobile direct observation treatment
MDR-TB	multi-drug-resistant TB
MIPA	meaningful involvement of people living with HIV
MMC	medical male circumcision
MSF	Médecins Sans Frontières
MSM	men who have sex with men
NEPAD	New Partnership for Africa's Development
NGO	non-governmental organization
NWICO	New World Information and Communication Order
PCM	please call me (message)
PDA	personal digital assistant
PEPFAR	President's Emergency Plan for AIDS Relief (United States)
PHW	peer health worker
PITC	provider-initiated testing and counselling
PMTCT	prevention of mother-to-child transmission
PSA	public service announcement
PSI	Population Services International
RCT	randomized controlled trial
SAPs	Structural Adjustment Programs

SCT	social cognitive theory
SIM	subscriber identity module
SMS	short message service
STI	sexually transmitted infection
TAC	Treatment Action Campaign (South Africa)
TB	tuberculosis
TRA	theory of reasoned action
TTM	transtheoretical model
UHIN	Uganda Health Information Network
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
USSD	unstructured supplementary service data
VCT	voluntary counselling and testing
WAP	Wireless Application Protocol
WHO	World Health Organization
WSIS	World Summit on the Information Society
XDR-TB	extensively drug-resistant TB

## --- CHAPTER ONE ---

### AN INTRODUCTION TO MHEALTH AND HIV/AIDS

This thesis examines some of the opportunities, challenges and complexities that characterize the use of information and communications technologies (ICTs) to foster human development and social change, focusing particularly on the potential of mobile phones to improve health outcomes in developing nations. My particular interest lies in the specific and daunting development challenges facing sub-Saharan Africa<sup>1</sup>—a region where health and development obstacles remain especially acute—and the potentialities for the use of ICTs to help address these challenges. The devastating scale of the AIDS epidemic is undoubtedly one of the most significant threats confronting the continent: more than 22 million people in the sub-Saharan region are living with HIV, millions are newly infected each year, and less than half of those in need have access to treatment (UNAIDS 2009). This imposes a tremendous strain on African families, communities, and nations. Hence, this thesis focuses specifically on HIV/AIDS, the role of communication-based interventions, and the possibilities for—and limitations to—developing innovative, locally appropriate, scalable and sustainable uses of mobile phones to support and advance HIV/AIDS work in sub-Saharan Africa.

#### 1.1 Overview and Background

When I first travelled to southern Africa in 2007, my intention was to explore the potential of community radio to address development objectives and advance socio-political change. Based on my experience in community radio in Canada, my interest in development,

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<sup>1</sup> Sub-Saharan Africa refers to the geographical region of the African continent south of the Sahara, and includes forty-eight countries (UN 2009). Although Djibouti, Somalia, and Sudan (and now, South Sudan) are often included in this region, they are not by the Joint United Nations Programme on HIV/AIDS (UNAIDS) or the International Telecommunication Union (ITU)—two important sources for statistics in my research—and hence these countries will be excluded here (ITU 2011; UNAIDS n.d.). While I am interested in examining this region as a whole, my fifth chapter will focus specifically on case studies from South Africa.



and research I had previously conducted on the subject, I was excited by the promise that community radio initiatives held for southern Africa. I could see that the communications landscape in this region was indeed radically different from that in North America, particularly with respect to the limited accessibility and significance of the Internet. Although community radio did indeed appear to hold great potential, I noticed another communications technology of remarkable ubiquity and influence: mobile phones. As I lived, worked and travelled across southern Africa over the following few years,<sup>2</sup> I encountered mobile telephony in the most unexpected places. From the remote pastoral villages in the mountains of Lesotho to Botswana's Okavango Delta to the coastal fishing communities in Mozambique, I found mobile phones not only surprisingly common, but also being used for diverse purposes. Citizens used this technology to create new business opportunities, to access news and information, and to communicate between previously isolated locales. As I became increasingly intrigued not only by this ubiquitous presence and cultural significance of mobile phones, but also by this range of imaginative uses, I began to wonder about the implications for communication-based health and development initiatives.

Working with a non-profit AIDS organization<sup>3</sup> in South Africa, I gained a deeper understanding of the immediate needs and challenges of HIV/AIDS work in this region, complicated both by the immense scope and intimidating complexity of the epidemic, and by the concurrent lack of resources with which to combat it. The stakes here remain critically high: the epidemic continues to be an acute personal, socio-political, and economic burden on this continent—the one most affected by AIDS—while it remains to be seen whether the

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<sup>2</sup> I first travelled throughout southern Africa from April through August 2007. I then returned to work in South Africa from July 2008 through August 2009, on placements funded by the Canadian International Development Agency and the American International Health Alliance. These placements—at a journalism department of a previously disadvantaged university and a local non-profit AIDS organization—afforded me first-hand knowledge and practical experience in the complex communications landscape of the country and in the challenges confronting HIV/AIDS-oriented health care service delivery in this context.

<sup>3</sup> Phomolong Care Centre in Springs, Gauteng (near Johannesburg).

material resources, financial support, and political will required to alleviate the crisis will be achieved and sustained. I began to see in a really practical way the potential for mobile phones to be integrated into health systems and AIDS interventions to harness this pervasive technology to achieve better results from limited resources. My previous academic studies had focused on critical media theory and ICTs for development (ICT4D), which refers to the use of ICTs in development practice with the aim of overcoming geographic barriers and social inequalities and supporting objectives as diverse as fostering human and socio-economic development, advancing health and education systems, and facilitating improvements in business and governance<sup>4</sup> (see, for example, Thioune 2003, Unwin 2009, and Wilson 2003). Based on this academic background, I could imagine the potential in marrying communication-based AIDS work with critical ICT4D perspectives on mobile phones. In reviewing literature on the subject, I discovered a number of individuals and organizations propounding similar hypotheses, and a palpable excitement amongst important international stakeholders concerning the integration of mobile phones with health and development initiatives.

The use of mobile phones in such contexts is indeed being attributed with the potential to improve citizens' access to health information and services, create efficiencies, and improve health outcomes, especially in developing countries (Feder 2010; Kahn et al. 2010; Mechael 2009; Vital Wave 2009). Early projects are already underway in a number of countries.<sup>5</sup> Despite this growing awareness and discussion there remains, however, a lack of critical analysis and evaluation by academics, policy-makers and non-governmental

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<sup>4</sup> The second chapter of this thesis will elaborate on this perceived potential, and explore some of the significant limitations of mainstream policy and academic approaches to ICT4D.

<sup>5</sup> For instance, initiatives in Thailand and the Philippines aim to increase medication adherence for tuberculosis patients through daily reminders via mobile phones, while projects in India and Uganda seek to raise HIV/AIDS awareness through interactive games and text message-based quizzes. In Rwanda, community health workers are using basic mobile handsets to collect and enter health data, download treatment guidelines, order medicine, and distribute public health alerts (Vital Wave 2009). These and other such initiatives will be examined in Chapter Four.

organizations (NGOs) of the success, scalability or sustainability of these initiatives. There is also an absence of critical media studies perspectives on this potential, and a lack of attention to either HIV/AIDS or African contexts specifically vis-à-vis mobile phones and health intervention. It thus became clear to me that the challenges faced by those responding to the AIDS epidemic are too urgent and complex, and the opportunities presented by the extensive reach of mobile phones are too significant to ignore: the point of intersection between these two critical realities must be explored. Such an exploration is necessarily interdisciplinary in nature. To this end, this thesis will bring together the fields of ICT4D (specifically in sub-Saharan Africa), communication theory on mobile phones (a key technology in the developing world), and health communication (specifically in relation to AIDS), with special attention to critical Africanist perspectives on each of these theoretical fields. In so doing, I will argue that this point of intersection between these fields should be of interest to critical media studies scholars, as the use of mobile phones to support and advance HIV/AIDS intervention in sub-Saharan Africa holds significant potential along the entire AIDS continuum from awareness and prevention programs to HIV treatment and care. I will use this theoretical framework to critically examine both the opportunities presented by the use of mobile phones in this context, and the corresponding potential problems, challenges, and limitations of marrying mobile telephony with HIV/AIDS work on the African continent.

## **1.2 The Exceptional Nature of AIDS**

Three decades into the epidemic, AIDS remains one of the most complex challenges facing the world. From its initially perceived status as a relatively limited epidemic affecting primarily socially marginalized minority groups, AIDS has grown to be recognized as a

pandemic<sup>6</sup> with truly global implications. Globally, more than 33 million people are currently living with HIV, and nearly 30 million more have already died of HIV-related causes (UNAIDS 2010). Those infected reside in all regions of the world, and cross all socio-economic strata and other demographic divides. This monstrous scale means that AIDS remains one of the most critical issues in global public health. It is not, however, just the immense dimensions of the pandemic that are challenging, nor is it strictly a matter of epidemiology; rather, it is the unique nature of this particular disease that makes AIDS a universal social, political, and economic challenge. There is still no cure and no vaccine against HIV. However, this challenge is not only biomedical: the virus affects people in their prime productive and reproductive years, creates expensive lifelong treatment needs, is intricately linked with sexuality and familial relations, and remains largely enveloped by intense social stigma, discrimination, and marginalization (Aggleton and Parker 2009; Edgar et al. 2008; Fuller 2008). More so than any other disease, AIDS is an epidemic of globalization, of poverty, of sexual politics, and of social vulnerability. Its impact is exacerbated by other socio-structural inequalities, including race, gender, sexuality, and global economic inequity, as the poorest and most vulnerable and marginalized are also the most severely affected (Barnett and Whiteside 2006; Welbourn 2008; White et al. 2009).

Moreover, as Paula Treichler suggests, AIDS is also an “epidemic of signification” (1999, 35). The discursive landscape of AIDS—with its proliferation of competing and contradictory meanings—constructs the very nature of the disease, with real implications not only for popular perception and cultural narratives, but also for public policy, medical practice, and scientific research. Indeed, the social dimension of the disease shapes its biological dimension. As Treichler explains, “AIDS exists at a point where many entrenched

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<sup>6</sup> Following UNAIDS’ *Terminology Guidelines* (2008), I make reference to AIDS as a “pandemic” to signify the global reach of the crisis and discuss the disease at this most general level. This pandemic is comprised of distinct epidemics in different parts of the world; I will use “epidemic” in discussion of these particular regional or national instances.

narratives intersect, each with its own momentum and context in which AIDS acquires meaning... the discourse of AIDS attaches itself to these legacies of difference and reinvigorates them” (1999, 35). Narratives of race, culture, privilege, gender, and sexuality collide, and a multiplicity of perspectives, meanings, moralities, and political agendas are mapped onto the disease, with anticipated and unanticipated material and ideological consequences.

To understand the exceptional challenges and complexities inherent in the unique nature of the AIDS pandemic—and to develop effective interventions to respond to this crisis—therefore necessitates a broad socio-political, cultural and economic perspective (Fuller 2008; Melkote et al. 2000; Susser 2009; Welbourn 2008; White et al. 2009). Such analyses and responses move beyond the limited bio-behavioural and biomedical approaches to afford more holistic interventions to address the pandemic.<sup>7</sup> In emphatic agreement with Bharath-Kumar et al. (2009), Fuller (2008), and Melkote et al. (2000), I contend that an integral facet of such a holistic response is communication. This centrality of communication to AIDS intervention, in addition to the manner in which cultural and discursive constructions shape the disease and responses to it in material ways, makes any analysis of the pandemic and related responses a suitable topic for media studies research. Hence, this thesis takes a critical media studies approach, with the intent to augment more traditional health-oriented and policy perspectives.

Given this enormous scope and multi-faceted nature of AIDS—and the corresponding complexity of analysis and response required—the pandemic is increasingly recognized as a threat to social development, economic growth and stability, and national and international security. Of particular significance here is the inextricable link between AIDS and

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<sup>7</sup> I will critique these paradigmatic intervention models in Chapter Three, focusing particularly on the inadequacy of hegemonic behaviour change health communication models such as the “ABC” (Abstain, Be faithful, Condomize) approach to prevention. See, for example, Airhihenbuwa and Obregon (2000) and Green (2003).

development. Situating AIDS in such a holistic framework means acknowledging AIDS as a social, political, and especially a development issue, perhaps as much as a health challenge (Fuller 2008, 29; Whiteside 2005). Indeed, the Millennium Development Goals (MDGs)<sup>8</sup> include action on HIV/AIDS as one of the primary eight goals: Goal Six aims to achieve universal access to treatment by 2010, and halt and reverse the spread of HIV by 2015, the end date for all of the goals (UN 2010). Setting the agenda at the highest political level, the MDGs explicitly position AIDS as a critical imperative not just for global health, but for human development more broadly.<sup>9</sup> However, as I have highlighted, the pandemic continues to devastate many communities and nations, and much remains to be done to mitigate the effects of HIV and AIDS globally. As the Joint United Nations Programme on HIV/AIDS (UNAIDS 2009) reports, for every 100 people that commence antiretroviral therapy (ART) globally, 250 are newly infected with HIV. While this reveals the continued critical deficit in access to treatment, it also underscores the continued imperative of prevention efforts. Nowhere is this need greater—and nowhere is the link between AIDS and development more explicitly linked—than in the region where the vast majority of these new infections occur and where there remains by far the greatest gap in treatment access: sub-Saharan Africa (UNAIDS 2009; WHO 2010).

### **1.3 AIDS and Africa**

In mainstream AIDS discourses, the African continent is frequently presented as tortuously entangled with the pandemic, imaginatively wrapped up in narratives of blame and exoticism, sexual Otherness, and widespread social devastation. Discourses pertaining to

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<sup>8</sup> The MDGs are a set of broad and ambitious targets for improving human well-being around the globe which were adopted by world leaders in 2000 and function as shared guiding objectives for all United Nations member states and most leading international agencies (Hecht et al. 2006; Pronk 2004; UNDP 2005).

<sup>9</sup> Moreover, the need to mitigate the impact of the AIDS pandemic is significant not just for Goal Six specifically, but also for other goals addressing maternal health, child mortality, gender equality, primary education, and poverty reduction in general, as the effects of HIV and AIDS undermine efforts to address any of these challenges (Hecht et al. 2006). Quite simply, without dramatic and sustained action on AIDS, the MDGs will never be achieved.

‘African AIDS,’<sup>10</sup> in particular, tend to conjure images of suffering, hopelessness, and inevitability. It is important to recognize, however, that there is not one single ‘African epidemic’—no single shared history, experience, or response to AIDS—just as there is no typical pan-African identity, culture, or lifestyle (Fuller 2008; UNAIDS 2009; Whiteside 2005). Instead, there are many different epidemics, sometimes within a single country: experiences of AIDS vary significantly between and within affected African nations.<sup>11</sup> While it may be impossible to chart a truly pan-African AIDS story, it is undeniable that sub-Saharan Africa is more deeply affected by the pandemic than any other region worldwide. More than two-thirds of people living with HIV in the world reside in sub-Saharan Africa, and the region accounted for nearly three-quarters of AIDS-related deaths in 2008 (UNAIDS 2009, 21). While the last decade has brought signs of hope—the epidemic appears to have stabilized in a number of African nations and notable improvements have been made in access to treatment—the crisis remains acute (UNAIDS 2009). Despite the slight decline in overall HIV prevalence, the number of people living with HIV in sub-Saharan Africa has actually increased (in part due to the life-prolonging benefits of ART), the region accounted for the vast majority of new HIV infections worldwide among both adults (68%) and children (91%) in 2008, and more than 14 million children have lost one or both parents to the epidemic (UNAIDS 2009, 21). This is an unprecedented threat to the social, cultural,

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<sup>10</sup> I make reference to ‘African AIDS’ in quotation marks in order to draw attention to the pervasive discursive constructions and representations of the AIDS epidemic in Africa as though it were something wholly unto itself. Both Treichler (1999) and Cindy Patton (1999) have discussed the “invention” of a (heterosexual) “African AIDS” as distinct from the Euro-American “AIDS” afflicting primarily homosexuals, drug users, and minority groups. Patton suggests this displacement of danger onto the exotic Other serves not only to promote a new kind of colonial domination, but also to conceal Western heterosexual vulnerability. I will discuss these cultural and discursive constructions in greater detail in Chapter Three, particularly in relation to how they have shaped health communication theories, models, and interventions in HIV and AIDS.

<sup>11</sup> For instance, the experience in Uganda—where the epidemic skyrocketed in the early 1990s to an HIV prevalence of 25% of women attending antenatal clinics, but had fallen dramatically to less than 6% by 2005 as a result of concerted action by the state (Whiteside 2005)—is sharply contrasted by the situation in South Africa. In 1990, just 0.7-0.8% of pregnant women in South Africa tested positive for HIV, but after years of government inaction (in part distracted by the transition to democracy) and a protracted period of AIDS denialism, this had increased to 29% in 2008 (Thornton 2008, 153; UNAIDS 2009, 28).

economic, and political health of the continent. Southern Africa<sup>12</sup> clearly bears the worst of the epidemic: the nine countries with the highest HIV prevalence are found in this subregion, all reporting adult HIV prevalence greater than 10%<sup>13</sup> (UNAIDS 2009, 27).

Sub-Saharan Africa is not only unique in the scale of its HIV epidemic, but also in the continued disproportionate impact on women and girls. This is the only region of the world where more women than men are infected—women account for 60% of HIV infections—and young women are particularly vulnerable (Fuller 2008, 5; Kalipeni et al. 2009; UNAIDS 2009, 22). Women not only suffer from greater susceptibility to HIV transmission physiologically (UNAIDS 2009, 22; Whiteside 2008), but as Linda Fuller (2008) chronicles, African women experience a number of additional socio-cultural, economic, educational, legal and political vulnerabilities that contribute to their continued position of unequal and exceptional susceptibility. Yet, these women are often invisible in AIDS discourses, and the unique dimensions of their particular vulnerability have seldom been adequately acknowledged in discussions of African (or other) AIDS epidemics<sup>14</sup> (Susser 2009). Hence, a gendered analysis is a necessary aspect of any meaningful examination of the impact of HIV and AIDS on this continent, and must be integrated in the development of effective interventions.

The situation is particularly critical on the African continent because AIDS exacerbates pre-existing health challenges and overburdens already-strained health care systems struggling to combat malaria, tuberculosis, diarrhea, cholera, and other often chronic

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<sup>12</sup> Southern Africa refers to a subregion of sub-Saharan Africa that includes: Angola, Botswana, Comoros, Lesotho, Madagascar, Malawi, Mauritius, Mozambique, Namibia, Seychelles, South Africa, Swaziland, Zambia and Zimbabwe.

<sup>13</sup> Swaziland has the most severe level of infection, with an HIV prevalence of 42% among prenatal clinic attendees in 2008 and an overall adult prevalence estimated at 26% in 2007, while South Africa has the largest epidemic in terms of population size, with 5.7 million people living with HIV in 2007 (18% of adults aged 15-49) (UNAIDS 2009, 27-28).

<sup>14</sup> In recent years, however, gender perspectives have begun to appear more often in AIDS discourses, particularly within the UN system of organizations and the International AIDS Society conferences. International representatives—perhaps most notably Stephen Lewis, former Special Envoy for HIV/AIDS in Africa, Peter Piot, former Executive Director of UNAIDS, and Mary Robinson, former UN High Commissioner for Human Rights—have advocated the need for increased attention to the feminization of AIDS (Lewis 2006; Susser 2009).



diseases, in addition to the challenges of malnutrition, parasites, and infection (Fuller 2008, 11). Although it is beyond the scope of this thesis to examine the complex political and socio-economic histories of health crises on this continent, it is important to contextualize here the severity of these obstacles. Sub-Saharan Africa is enduring these tremendous health challenges, while significantly lacking both trained medical personnel and adequate public health infrastructure. With only 14% of the world's population, this region faces 24% of the global burden of disease, yet has just 3% of the world's health care workers (Vital Wave 2009). By 2015, sub-Saharan Africa will face a projected shortage of 800,000 doctors, nurses and midwives (Scheffler et al. 2009). The demand for hospital beds, medicines, laboratory services, and other health care resources far exceeds what is available (Fuller 2008, 11). Indeed, 35 of the 42 lowest-ranked countries in the Human Development Index<sup>15</sup> are found in sub-Saharan Africa, indicating a lack of health infrastructure, trained health care personnel, and financial capacity to address the epidemic, in comparison to more developed nations (Fuller 2008, 13; UNDP 2010). While this exceptional challenge—to address the worst epidemic with the fewest resources—bears upon all aspects of HIV/AIDS intervention, it is particularly dire in relation to achieving universal access to treatment, an MDG that will not be possible for 2050, let alone the set target of 2010, without concerted action on both prevention and treatment access (MSF 2010; WHO 2010). Although drug costs have decreased dramatically,<sup>16</sup> universal access remains a formidable economic and infrastructural

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<sup>15</sup> The Human Development Index is a broad measure of development encompassing health, education, and income, with the aim of measuring progress on human- rather than economic-centered development (UNDP 2010, 13).

<sup>16</sup> At the peak of the epidemic in sub-Saharan Africa, the prices of medicines—tens of thousands of dollars per patient per year in the mid-1990s—were such that HIV/AIDS treatment was widely perceived as infeasible in developing nations (Bass et al. 2008, 154), “condemning 90 per cent of the world's HIV-positive population to a painful and inevitable death” (Robins 2004, 663). This affordability barrier had been aggravated by the legacy of the International Monetary Fund (IMF) and the World Bank's structural adjustment programs (SAPs) of the 1980s, which ultimately resulted in weakened health systems in many African nations through reduced public spending and the transfer of responsibility for health to individuals as consumers, at the same time as the AIDS epidemic was emerging (White et al. 2009). As a result of widespread activism and fierce generic competition, the cost of a first-line regimen of antiretrovirals (ARVs) in developing countries has dropped dramatically: by 2010 the cost was US \$67 per patient per year—a staggering 99% reduction in price from ten years prior (MSF 2010, 4).

challenge, beyond reach for many African states. Consequently, the need for innovative interventions that capitalize on available resources and improve effectiveness and efficiency remains paramount. It seems pertinent to explore whether new communications technologies—specifically the pervasive reach of mobile phones in the African context—can be harnessed to this end.

#### **1.4 Mobile Telephony and the African Communications Landscape**

Any examination of the global communications landscape reveals the unparalleled significance of mobile phones in the developing world. By the end of 2011, there were almost 6 billion mobile cellular subscriptions worldwide, with more than three quarters of these subscribers living in the developing world (ITU 2011b). Mobile telephony is thus becoming increasingly ubiquitous throughout developing countries, from less than 5% penetration in 2000 to nearly 80% at the end of 2011—higher than any other communications technology in the past (ITU 2009, 2011b). By contrast, only 25% of citizens in the developing world had access to the Internet this same year<sup>17</sup> (ITU 2012). The significance of mobile phones in this context may be difficult to comprehend in a country like Canada, where the number of Internet users actually exceeds mobile subscriptions (ITU 2011b). Yet for much of the world, mobile phones remain a technology of pivotal importance and a resource with great potential for those engaged in communication-based development initiatives. This is especially true for the African continent.

Just as the landscape of the AIDS epidemic is unique in sub-Saharan Africa, so too is the region's communications landscape. In this context, mobile phones have acquired an unprecedented significance in recent years, both in their relative pervasiveness and in their

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<sup>17</sup> The penetration rates of these two technologies may not be totally comparable, as there are marked qualitative differences in meaningful access between owning a personal phone and having potential access to the Internet via community telecentres or cybercafés. The rapidly increasing uptake of mobile broadband subscriptions (ITU 2012) is further blurring the distinction between these two technologies. I will discuss the notion of 'access' in greater detail in Chapter Two, as I examine the extent to which these barriers to access inhibit or enable the use of mobile phones relative to other ICTs.

flexibility of use. Less inhibited by traditional access barriers that hinder the widespread use of many other communications technologies—including geography, socio-economic status, infrastructure such as electricity, and to some extent language and literacy—mobile phones have attained a leading role in local communications contexts. Whereas only 12.8% of people in sub-Saharan Africa used the Internet by the end of 2011—and only 0.2% had access to high-speed, high-capacity broadband Internet—the percentage who are mobile subscribers has already exceeded 53%, with a faster growth rate than any other region of the world<sup>18</sup> (ITU 2010, 2011b). This extraordinary growth has resulted in large part from unique aspects of mobile telephony that are well-suited for the African communications landscape: the relatively low cost of deployment of cellular networks in low-income and rural areas, the advent of affordable prepaid services, the lower skills base required for use, and the lack of existing fixed-line infrastructure, resulting in latent demand for communication services (Srivastava 2008).

Of course, there is remarkable variation in the penetration rates of mobile telephony in different African nations (ITU 2011). In addition, the technology is being used for diverse ends in different places, from personal communication to citizen journalism, from business opportunities and financial transactions to public endeavours related to education and governance. One noticeable trend has been the increasing use of Short Message Service (SMS) text messages as a common means of communication. This has been true globally,<sup>19</sup> but this communication format appears especially significant in Africa, where 95% of subscribers are using a prepaid service, and SMS is often more affordable than a voice call (ITU 2009, 17; Srivastava 2008). SMS is also significant in opening up new potential avenues for engagement with African citizens for diverse purposes, as I will explore in this

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<sup>18</sup> The countries of Comoros and Mauritania are excluded from ITU's statistics for sub-Saharan Africa.

<sup>19</sup> The ITU estimates a total of 6.1 trillion SMS messages were sent globally in 2010, an equivalent of close to 200,000 text messages every second.

thesis. Mobile telephony is, of course, being used with creativity, innovation, and diversity all over the world. In sub-Saharan Africa, though, where the Internet and other ICTs remain largely inaccessible and cellular penetration is growing at unprecedented rates, the corresponding opportunities newly presented by the increasing predominance of mobile phones are worthy of close examination. With respect to development agendas—including interventions in health—this growing ubiquity of mobile phones clearly calls for a re-examination of ICT-focused development projects and priorities in the African context.

### **1.5 “mHealth” in the Developing World**

In the past few years, there has been much public recognition and discussion by national governments, bilateral and multilateral organizations, and civil society concerning the perceived potential of integrating health and ICT policies (Chetley 2006; Mechael et al. 2010; Vital Wave 2009; Wootton et al. 2009). Significant attention has been given to electronic health, or ‘eHealth’ initiatives, which use ICTs to deliver health information and services. Integrating *mobile* communications technologies with health intervention—a subsection of eHealth commonly referred to as ‘mHealth’—offers some particularly promising solutions.<sup>20</sup> For instance, mobile telephony can be used by public, private, and non-profit health service providers to connect with citizens, to minimize the impacts of some geographic and social barriers to health, to improve access to health information and services, and to make health intervention more efficient and effective, especially in challenging rural or resource-limited contexts. In international health discourses, mHealth is not a new concept. Building on the already voluminous work on eHealth, many scholars and policy-makers have been theorizing extending initiatives that deliver health information and services through ICTs to include mobile phones for almost a decade (Chetley 2006; Kaplan 2006; Istepanian

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<sup>20</sup> Although mHealth encompasses a broad range of mobile communication technologies, including sophisticated devices like Personal Digital Assistants (PDAs), I am most interested in examining here the potential of mHealth initiatives that make use of simple mobile phones, which are more widespread in the African context.

and Lacal 2003; Mechael 2009; Wootton et al. 2009). However, these discussions have until recently focused primarily on potential or existing projects in developed countries, and frequently on those targeting health issues common in Western nations, such as mHealth programs for smoking cessation or diabetes management (Cole-Lewis and Kershaw 2010; Fjeldsoe et al. 2009). By early 2010, there were already 5,000 clinical and consumer health care applications available for the iPhone and other advanced mobile phones (Health Management Technology 2010), and by August 2012 Apple alone is expected to offer close to 20,000 of these applications (Gullo 2011). Although many of these applications remain available and relevant only in more developed regions, the promise for mHealth to enhance health systems and intervention has been acknowledged by governments and organizations worldwide, and by 2010 more than 75% of countries reported at least one mHealth initiative (ITU 2010b).

The potential for mHealth to improve health service delivery actually appears to be greatest in the developing world, given the remarkably high penetration of mobile telephony and the scarcity of health resources: the reach of mobile coverage in the developing world is greater than any other technology or any health care infrastructure or services, such as access to doctors, hospitals, and essential medicines (Vital Wave 2009). A number of important stakeholders in international development have not only acknowledged this potential, but also acted to incorporate mHealth initiatives into their recent programming.<sup>21</sup> Rather than introducing new ICTs (e.g. computers and Internet) as vehicles to promote development or health care delivery, the approach taken by many mHealth initiatives is based on assessing

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<sup>21</sup> For example, the United Nations Development Programme (UNDP), the World Health Organization (WHO), the Centers for Disease Control and Prevention (CDC), Canada's International Development Research Centre (IDRC), the United Nations Foundation, and the President's Emergency Plan for AIDS Relief (PEPFAR) of the United States have all developed or supported projects specifically oriented to integrating mobile phones into health systems in the developing world. A number of initiatives have also been spearheaded by multinational telecommunications corporations and their non-profit foundations (e.g. Vodafone Foundation, MTN, Nokia, Microsoft Research, and Voxiva).

existing local communications landscapes—in which mobile phones are dominant—and transforming development and health care models accordingly. Although such an approach appears promising, particularly in terms of enhancing efficiency and cost-effectiveness of project roll-out, critical analysis of the potential problems and limitations remain largely absent.

As I will outline in Chapter Four, the pace of mHealth adoption and experimentation has been rapid. A report released by The UN Foundation and Vodafone Foundation Technology Partnership in 2009 highlighted more than fifty significant mHealth initiatives underway in the developing world; approximately one third of those projects are located in sub-Saharan Africa (Vital Wave 2009). By June 2012, there were 625 mHealth projects and services globally including over 200 in sub-Saharan Africa (GSMA 2012c). Although many of these initiatives are still in pilot or demonstration phases, mainstream policy literature suggests a perceived potential for mHealth to be employed to help strengthen or transform weak health care systems by expanding public health awareness and education, facilitating connections between patients and providers, assisting training and providing information resources for community health workers (CHWs), monitoring and supporting medication adherence, improving diagnostics and treatment support, and even tracking epidemic outbreaks<sup>22</sup> (Curioso and Mechael 2010; Feder 2010; Iluyemi 2009; Kahn et al. 2010; Kaplan 2006; Mahmud et al. 2010; Vital Wave 2009). While there has been a significant proliferation of discussion, reports, and research on mHealth in recent years,<sup>23</sup> including some attention to its potential in sub-Saharan Africa, there remains: (1) a lack of critical

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<sup>22</sup> It is important to acknowledge the many ways mobile phones can be used as tools to help improve health outcomes simply by facilitating affordable, basic person-to-person or -institution communication—especially in areas with limited fixed-line infrastructure—such as connecting rural clinics and hospitals, allowing for easier ordering of supplies, or simply in affording individuals the possibility to call for medical help. However, this thesis is primarily concerned with the types of initiatives listed here, which are specifically designed around mobile phones.

<sup>23</sup> See, for example, the extensive literature review published in May 2010 by a research team at Columbia University that surveyed hundreds of such reports (Mechael et al. 2010).

analysis and evaluation, both clinically and economically, for local governments, service providers, and other organizations to justify scaling-up or supporting sustainable models (Mechael et al. 2010); (2) a surprising relative absence of critical media studies perspectives, despite these pursuits being grounded in communication for development; and (3) a lack of attention to the unique challenge of HIV/AIDS communication interventions, especially on the African continent.

### **1.6 The Case for mHealth in HIV/AIDS Intervention**

Mobile phones appear particularly well-suited to HIV/AIDS work in education, prevention, treatment, care, and support applications, and can potentially be used to overcome some of the traditional barriers to accessing essential information and services, such as geographic isolation, gender, and social stigma (Iluyemi 2009; Kahn et al. 2010; McKee et al. 2004; Mechael 2009). In addition to the more obvious role communication has to play in education and prevention initiatives, communication interventions remain essential throughout the entire continuum of outreach, testing, treatment, care, and support (Bharath-Kumar et al. 2009). Particularly in the African context, communication is essential to combat widespread stigma and misinformation, to facilitate the frequent reliance on non-professional medical personnel for treatment and support, and to provide information, education and communication (IEC) outreach critically needed for preventing infection, encouraging testing, and facilitating access to treatment (Bharath-Kumar et al. 2009; Fuller 2008; Iluyemi 2009; McKee et al. 2004; Swanepoel and Hoeken 2008; Van Damme et al. 2006). Indeed, I argue that the use of mobile phones holds significant promise and potential for two interrelated critical aspects of HIV/AIDS intervention: (1) facilitating outreach, prevention, and awareness programs; and (2) improving access to treatment, care, and support services. While treatment efforts are still critically dependent on acutely lacking health infrastructure,

human capacity, and material resources such as ARV drugs, the use of mobile phones can be approached as a way to stretch limited resources and improve effectiveness and efficiency of treatment and care.

After discussing HIV/AIDS mHealth applications more generally, this thesis will critically examine the potential for mobile phones to enhance both of these aspects of the AIDS response via a case study of the pioneering South African mHealth organization Cell-Life, which is presented in Chapter Five. Cell-Life is a non-profit organization based in Cape Town, that aims to “improve the lives of people infected and affected by HIV in South Africa through the appropriate use of technology” (Cell-Life 2009). The organization has developed a wide range of mHealth applications, harnessing diverse technological functionalities to support HIV-related communication in all aspects of awareness outreach and treatment support programs. With its varied approaches and areas of project focus, Cell-Life offers valuable insights into the potential opportunities in practical applications of mobile phones in these two interrelated aspects of HIV/AIDS work in an African context.

South Africa presents a particularly useful context within which to examine the issues and complexities surrounding mHealth interventions in HIV/AIDS, for several reasons: (1) the country can be considered the epicenter of the pandemic: it has the highest number of people living with HIV, partly due to the government’s devastatingly slow and counterproductive initial response to the crisis (Nattrass 2007; UNAIDS 2009); (2) with more mobile subscriptions than inhabitants, South Africa boasts one of the highest mobile penetration rates in sub-Saharan Africa (ITU 2011b); and, (3) a “Rainbow Nation” with eleven official languages and even more distinct ethnic groups (South Africa Department of Foreign Affairs 2008), South Africa’s extraordinary linguistic and cultural diversity presents considerable challenges for mHealth intervention design which, if critically addressed here,



may be applied meaningfully in other contexts of diversity. Therefore, projects piloted in South Africa are worthy of attention not only because of the acute need and the potential for success given the ubiquity of mobile phones, but also because such projects can potentially be quite instructive in predicting outcomes on the rest of the continent as mobile phone subscription rates continue to grow rapidly. A critical analysis of these examples can thus, it is hoped, assist in theorizing approaches to conceptualizing and implementing similar interventions in other locales.

The Cell-Life case study will allow me to interrogate some of the potential problems and limitations with mHealth in this context. Despite the potential I have outlined, a number of critical issues and challenges persist, including: the underlying problem of inadequate health care systems; the use of mobile phones as a technological fix for complex socio-political and economic problems; the potential for sustainability and scalability of the types of initiatives that have been piloted; the political economy of who is promoting, funding and implementing these projects, and the related implications of reliance on telecommunication companies for cellular service provision. There are also socio-cultural and ethical considerations including privacy and surveillance concerns; the types of evaluation mechanisms in place, or lack thereof; the level of community involvement and local knowledge incorporated into project design and implementation; and the forms of exclusion that may still occur along gender, socio-economic, language and literacy, or other lines.

Hence, this thesis examines the complex opportunities and challenges of developing innovative, locally appropriate, sustainable and scalable uses of mobile phones as instruments to support and advance HIV/AIDS work in sub-Saharan Africa. In so doing, it draws on diverse theoretical fields—most importantly, ICT4D (with a focus on mobile phones) and health communication (with a focus on HIV/AIDS)—to establish a multi-

disciplinary theoretical framework. However, the scope of this thesis is limited *only* to this particular point of intersection between these two fields; it is concerned with ICT4D and health communication only insofar as they inform mHealth in development contexts, and will not extrapolate its findings to comment on broader issues or debates within these fields. In addition, this thesis focuses on mobile phones to the exclusion of other potential uses of ICTs in HIV/AIDS work.

### **1.7 Research Objectives**

The *first* objective of this thesis is to situate mHealth in developing nations within an appropriate theoretical framework, primarily from a critical media studies perspective, rather than a health, policy, or computer science/design perspective. This theoretical context will establish a point of convergence between ICT4D and health communication. It will historicize this trend of mHealth within the broader context of ICT4D and discourse surrounding related development policies, perspectives, and practices of major global institutions such as the UN and the World Bank, as well as NGOs and national governments. The *second* objective is to identify the potential opportunities for mHealth applications to specifically address the HIV epidemic in sub-Saharan Africa, as well as the related challenges. It will be important to critically examine paradigmatic health communication approaches to HIV/AIDS work in developing nations, not only with respect to prevention and education programs, but also in theorizing the role of communication in treatment and support. This examination will interrogate biomedical and bio-behavioural models of HIV/AIDS communication interventions, particularly in African contexts, and discuss alternatives. The *third* objective is to critically examine real-life applications of mHealth models in order to identify the experienced complexities relating to mobile-phone based interventions to strengthen HIV/AIDS work in sub-Saharan Africa. It will examine the

experiences of such interventions specifically focused on two interrelated critical aspects of HIV/AIDS work—prevention outreach and treatment support—via a case study from South Africa. This examination will help reveal the challenges, limitations, and critical issues that inhibit effective realization of the perceived potential of mHealth in this context.

### **1.8 Research Questions**

Following these objectives, this thesis poses four sets of interrelated research questions:

1. How can we understand mHealth as informed by both ICT4D and health communication?  
How can it be situated in relation to eHealth, and in relation to the large body of ICT-focused development projects and priorities? What are the central health communication theories and models that inform mHealth interventions?
2. Why is there such a significant perceived potential in using mobile phones as tools to address the health challenges in developing nations? What are the potential mobile phone-based health applications that have been identified, promoted, or piloted in the Global South? More specifically, what are the opportunities to address the AIDS pandemic in particular? What is the need for communication interventions in HIV/AIDS work, beyond the widely acknowledged necessary role in prevention and awareness campaigns, and to what extent can mobile phones be employed to address this need?
3. Why may this potential be especially significant in sub-Saharan Africa? What are the unique aspects of both HIV/AIDS and the place of mobile phones in African communications landscapes that suggest such a promising marriage in this particular region? What are the practical experiences when these applications are realized on the ground in sub-Saharan Africa, and where the focus is on differing aspects of HIV/AIDS work?

4. What are some of the key challenges, concerns, and limitations with the merging of ICT and health policies and projects in general, and specifically with mobile phones and HIV/AIDS? What are the critical issues vis-à-vis mHealth partnerships with the public and private sectors? What are the dynamics or tensions between the profit motives of African and multinational cellular service providers and the social service goals of health care provision? What are the economic, ethical, socio-political, and cultural issues and obstacles?

## **1.9 Research Methods**

This thesis draws upon both primary and secondary research. In order to establish an interdisciplinary theoretical framework for mHealth and contextualize it within international ICT4D-related discourse, I have critically examined a number of texts from both scholarly and a range of mainstream sources, described below. My primary research informed my analysis of the Cell-life case study in Chapter Five.

### *1.9.1 Secondary Research*

My approach is predominately based on secondary research. This comprises two elements: in-depth critical research and archival analysis.

#### In-Depth Critical Research

This secondary research seeks to establish a theoretical grounding for my thesis by conducting a critical review of relevant academic literature. As outlined above, this involves bringing together the fields of ICT4D (specifically mobile phones), health communication (specifically HIV/AIDS), and critical literature on the socio-political, economic, ICT, and health context of sub-Saharan Africa. Although this research primarily focuses on the region as a whole, I paid special attention to literature focusing on South Africa to more fully contextualize my case study.

### Archival Analysis

This component of my secondary research involved critical analysis of a wide variety of texts, from both scholarly and mainstream sources, related to the use of mobile phones in health interventions in developing countries. To begin with, this analysis included examination of peer-reviewed academic literature, but this body of literature is quite small, given the nascent stage of the field of mHealth. Hence, I also chose to include in my analysis an extensive amount of ‘gray’ literature<sup>24</sup> because of its particular importance to the field of public health, often informing health policy, programming, and practice. As well, both gray and scholarly evidence should be included in reviews of new, innovative, and rapidly evolving topics in order to help find ‘difficult to locate’ studies, reduce publication bias, and depict a more accurate picture of interventions (Dobbins and Robeson 2006; Hopewell et al. 2007; Howes et al. 2004). Thus, I focused primarily on related reports and policy documents by significant international institutions such as those in the United Nations system of organizations and agencies (WHO, UNAIDS, ITU, World Bank), governments, NGOs, and research institutions. This analysis primarily informed my fourth chapter, in which I survey the range of applications that these major stakeholders perceive to hold significant potential. In addition, this archival analysis involved research garnered from publicly available websites and other relevant documents produced by or about the organization I profile in my case study, Cell-Life, from 2001 (when Cell-Life began as a research project at the University of Cape Town) to May 2012.

#### *1.9.2 Primary Research*

My primary research focuses on the processes of design and implementation of

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<sup>24</sup> Gray literature refers to material produced by all levels of government, academics, research centres, associations and societies, professional organizations, and industry, but which has not been formally published, has limited distribution, or is unavailable through traditional channels (Dobbins and Robeson 2006; Howes et al. 2004). Gray literature includes policy briefs, white papers, technical reports, fact sheets, working papers, and other reports.

HIV/AIDS-oriented mHealth interventions, as experienced by Cell-Life, a leading organization in African mHealth, based in South Africa. As discussed above, I have chosen South Africa for its extraordinarily high mobile phone penetration rate, the immense scale of its HIV/AIDS epidemic, its challenging linguistic and cultural diversity, and my practical experience living and working in this area. I have selected this particular non-profit organization because of its longevity, the large scale of some of its projects, and the broad scope of its HIV-oriented work. (Cell-Life initiatives address the full range of the AIDS continuum, from education and awareness to HIV care and treatment support, at varying degrees of project scale.) Moreover, I selected Cell-Life because of its diverse collaborations and partnerships with private partners and donors, as well as the South African government and the country's public health sector.

To support my case study analysis, I interviewed Katherine de Tolly, Cell-Life's mHealth Project Manager and Senior Researcher. The interviewee was selected based on her expertise in the subject, her senior position in the organization, and her involvement with the research components of Cell-Life's work (as opposed to the more technical engineering aspects, which are less relevant to the focus of this thesis). Thus, she was able to comment on the organization's experiences with conceptualizing, developing, and implementing HIV/AIDS mHealth projects, including the processes of health communication message design and delivery. This interview data was necessary to augment the limited available literature and documentation (both published and gray literature) describing Cell-Life's projects, research, and experiences. It must be stressed that the level of in-depth reflection and insight about the experienced challenges and complexities inherent in this type of mHealth intervention that I sought was not available in other forms at the time of writing. This is partly because of the novelty and pilot-dominated nature of the field at present, and

partly because the existing academic literature on mHealth has primarily come from the fields of computer science and public health, rather than from critical communications. Hence, the objective of this interview was to garner in-depth critical reflection to inform my case study analysis and, if possible, to identify commonalities with other project experiences and continuities with ICT4D and health communication theory not specific to mobile phones.

To this end, I conducted an in-depth, open-ended, semi-structured, qualitative interview via telephone with de Tolly in May 2012. This free format was selected with the aim of affording a richer depth of observational data on the experienced complexities involved in engaging in these types of mHealth initiatives, and to foster opportunities for exploration of unexpected insights and reflections. In this interview, I was specifically concerned with acquiring information to deepen my understanding of: (1) the motivations and processes of Cell-Life's project conceptualization, design, and development; (2) barriers and challenges to design or implementation; (3) experiences of the collaborative partnership model; and (4) updated project information and outcomes. This qualitative research was based on a grounded theory approach—theories emerging from my analysis were inductively derived from research (Glaser and Strauss 1967). Understandings or explanations of how the particular patterns observed in this case study inform the theories I bring together in this thesis are grounded in the data gathered through this interview about the informant's perspectives and experiences.

### **1.10 Summary**

In sum, this thesis aims to make the following contributions: (1) provide a critical overview of selected mHealth initiatives in sub-Saharan Africa, contextualized within a theoretical framework of ICT4D and health communication; (2) explore the unique opportunities and challenges for HIV/AIDS-oriented communication interventions in

development contexts; (3) delineate the ways in which health communication theories and models, as well as ICT4D theory and discourse inform the shaping of mHealth interventions; (4) assess the range of potential applications of mobile phones to address the HIV/AIDS epidemic specifically in sub-Saharan Africa; (5) drawing on a practical case study, identify and elaborate on the limitations and critical issues related to mobile phone-based interventions to strengthen and advance HIV/AIDS work in this region; and (6) contribute to a critical media studies perspective on the complex opportunities and challenges of developing effective, sustainable, and locally appropriate uses of mobile phones to support HIV/AIDS interventions in African contexts.

This thesis will be structured into two distinct parts—the first focused on theory and the second on applications and analysis—and each part will be comprised of two separate chapters. Part One of this thesis establishes a theoretical framework for a critical media studies perspective on mHealth which draws on two principal fields: ICT4D and health communication. I will address each of these in separate chapters. Part Two will then explore the point of convergence of these two fields in an applied context, identify the opportunities and successes associated with mHealth in developing nations, and discuss an AIDS-oriented case study to highlight the principal issues and challenges accompanying this type of mHealth intervention in sub-Saharan Africa.

Following this introduction, then, the second chapter of this thesis highlights key critical ICT4D literature that interrogates the perceived links between ICT and development. It discusses the significant limitations to mainstream policy and academic approaches to ICT4D, focusing specifically on the importance of mobile phones in the sub-Saharan African communications landscape. Chapter Three discusses health communication in relation to HIV/AIDS, and critiques the dominant bio-behavioural models, which inadequately



acknowledge the complex web of factors that contribute to HIV vulnerability. In considering the role of communications interventions in HIV/AIDS work, this chapter argues the need for communication-centric approaches not only to prevention intervention, but also to treatment and care, which have traditionally focused on a biomedical model. Both of these chapters will also incorporate significant theoretical research on the socio-political, economic, ICT, and health contexts of sub-Saharan Africa, drawing on critical Africanist perspectives on the role of ICT4D and health communication in this region.

Beginning Part Two, the fourth chapter of this thesis surveys the field of mHealth and identifies the range of possible applications of mobile phones vis-à-vis health—with emphasis on those most relevant to health communication for HIV/AIDS—that have been theorized or initiated in the sub-Saharan African context. In analyzing the perceived potential of mobile phones to improve health care delivery and public education through enhanced connections between citizens, health care workers, health information networks, and public health organizations, this chapter also critically discusses some of the limitations, and scholarly and policy-oriented critiques of these applications. Chapter Five draws upon a case study of Cell-Life to examine the challenges and complexities inherent in employing this type of ICT4D to address the pandemic, and highlights critical issues in African mHealth interventions in HIV/AIDS. Through discussion of Cell-Life’s experiences alongside issues raised in other mHealth literature, this chapter critically examines issues surrounding privacy, ethics, and corporate and political involvement. It also examines potential barriers to access and usage that hinder many realizations of mHealth projects, including gender, language, literacy, training, financial sustainability, scalability, government cooperation, and dependence on inadequate pre-existing health infrastructure.

Following this analysis, the concluding chapter of this thesis summarizes the central findings of my research, articulating the opportunities, challenges and complexities that characterize the use of mobile phones as instruments to support and advance HIV/AIDS work in sub-Saharan Africa, and explaining why this point of intersection between ICT4D and health communication should be of interest to critical media studies scholars, as well as health and development researchers and practitioners more generally. It outlines my conclusions concerning the most critical issues and barriers to developing and implementing effective mHealth interventions to address the pandemic, and briefly discusses some more prescriptive policy-oriented conclusions about the preconditions necessary to achieve success, scalability, and sustainability.

## **PART ONE: A THEORETICAL FRAMEWORK FOR MHEALTH**

### **--- CHAPTER TWO ---**

#### **ICT4D AND MOBILE PHONES IN AFRICA: PROMISE OR PANACEA?**

During the past few years there has been considerable media hype, and growing excitement among health and development policy makers and practitioners, regarding the supposedly ‘revolutionary’ and ‘unprecedented’ potential of mobile phones to improve health outcomes in developing countries. I argue, however, that mHealth should not be framed as a profoundly new phenomenon. Rather, we can better understand mHealth as the latest development in a long history of technology- and communication-based health and development initiatives, informed by a diverse legacy of theories, strategies, ideologies, and the past experiences of both successful and unsuccessful projects and policies. In order to historicize and contextualize mHealth in this way, I will separately explore and critique the theoretical underpinnings of two fields—ICT4D (in this chapter) and health communication (in Chapter Three)—in order to establish a theoretical framework for mHealth from a critical media studies perspective. I will then bring these fields together and examine their point of convergence—mHealth applications in developing nations—more closely in Chapters Four and Five of this thesis.

Certainly, ICTs have tremendous potential to be leveraged as instruments of development and social change. This potential has been widely acknowledged by academics and practitioners alike. However, to avoid an uncritical celebration of this potential, we must nuance the promise of ICT4D with some of its potential limitations and critical issues. This chapter, then, will interrogate the perceived links between ICT and development, highlighting key ICT4D literature and discussing some of the limitations of mainstream policy and academic approaches to ICT4D. In so doing, I will focus particularly on mobile

phones and the communications context of sub-Saharan Africa. I will begin by chronicling the changing theoretical paradigms and practical approaches to international development over the past half century as they relate to the deliberate application of communication technologies, strategies, and processes to achieve development objectives. By historicizing the relationship between communication and development, I will highlight the ways in which much of the contemporary mainstream discourse about ICT4D is imbued with similar technologically determinist and utopian narratives to those which have accompanied myriad other technologies in the past, conceptualizing technology as a marker of progress and a panacea for a host of social, political, and economic challenges. This context will afford a more nuanced examination of the frequently proclaimed benefits of ICTs, including their capacity to overcome geographic barriers and social inequalities in poor and marginalized communities around the world, and to foster a broad range of social advances in areas as diverse as health, education, agriculture, commerce, economic growth, democracy and ‘good governance’. Unpacking these promises and the related concepts of the ‘digital divide’ and the ‘information society’ will involve problematizing notions of ‘access,’ ‘participation,’ ‘communication,’ and ‘development’ in relation to ICTs, and will reveal that in many instances the rhetoric of ICT4D constitutes an apolitical, ahistorical, technical solution to complex social challenges, obfuscating broader socio-political and economic contexts and constraints. Moreover, this context will establish a framework for discussing critical Africanist perspectives on the promises and utopian visions promulgated by the proponents of ICT4D, highlighting concerns about the devaluation of indigenous knowledge and culture, and the continued dangers of technological and economic dependency on the West.

My focus will then briefly narrow to consider the limitations of ICT4D approaches with respect to one technology in particular which is rapidly gaining significance in African

contexts: mobile phones. I will discuss the roles of mobile phones in the sub-Saharan African communications landscape, aspects of mobile telephony which are particularly well suited for this milieu, and the extent to which traditional barriers to technological access inhibit or enable the use of mobile phones relative to other ICTs. Notwithstanding these critiques of ICT4D, I will underscore the genuine potential that the use of ICTs can indeed offer for democratic engagement and participatory social change. I will highlight the particular possibilities presented by newer ICTs—paying particular attention to mobile phones—that afford greater potential for two-way and bottom-up communication, and present arguments from critical ICT4D literature on the importance of embracing endogenous, participatory, dialogical, context-specific, and process-oriented approaches to ICT4D.

## **2.1 Communication for Development: From Modernization to Multiplicity**

For more than half a century, communication and development have been conceptually intertwined in a relationship characterized by ambiguity, contestation, and critical debate. Communication is now recognized by many academics, policy makers, and practitioners as occupying a place of crucial importance in the field of international development—often referred to as “Communication for Development.” Yet there remains much conceptual ambiguity and confusion as to what this umbrella term actually encompasses, and whether this is even an appropriate name to represent the diverse ideologies, perspectives, approaches, and methodologies that constitute communication in the service of development (Eribo 2004; Waisbord 2001; Wilkins and Mody 2001). In some respects, the field can be portrayed as a chameleon, with different names reflecting different development eras and paradigms—the nebulous and fluid nature of its terminology producing definitions and boundaries that are flexible and overlapping both in theory and in practice, meaning different things to different scholars and practitioners in different historical

and socio-political contexts (Bessette 1996; Melkote 2002, 419; Quarry and Ramírez 2009, 6; Servaes 2008, 15). As such, what I refer to here as Communication for Development has also been known as “Development Communication,” “Social Communication,” “Development Support Communication,” “Communication for Human Development,” “Strategic Communication,” and “Communication for Social Change” (Quarry and Ramírez 2009; Colle 2008; McAnany 2010).

In many traditional academic and practitioner approaches—and still in much contemporary mainstream institutional practice—communication has often been relegated to playing the ‘second fiddle’ in development work, perceived as only offering tactical support in the pursuit of other loftier objectives (Waisbord 2007). However, this conceptualization of communication’s role in development has been frequently contested, with many academics and practitioners suggesting rather that communication should be a main goal in and of itself, positioned at the centre of whatever constitutes ‘good’ development (Quarry and Ramírez 2009). Hence, I choose to use the term ‘Communication for Development’ in keeping with a more strategic and foundational treatment of communication interventions and programs in development activities. Although these various approaches and labels have naturally resulted in many competing definitions, we can understand that, in the most general sense, Communication for Development refers to *the planned application of communication research, theory, strategies, processes, and technologies to engage in social change and advance goals of social betterment as identified by institutions and communities* (Bessette 1996; Colle 2008; Mody 2002; Rogers and Hart 2002; Servaes 2008; Wilkins and Mody 2001).

Much of the confusion and ambiguity concerning what exactly comprises Communication for Development stems from the conceptually complex and flexible nature

of each of its two components: ‘communication’ and ‘development’ (Eribo 2004). Thus, we can better understand any particular Communication for Development model by exploring the ways in which it conceptualizes each of these two components. In a historical context, we can identify a general shift from the postwar thinking on development, which frequently emphasized Eurocentric, top-down, economic growth-oriented models, to the contemporary focus—at least in theory and in the rhetoric of major international development institutions, if not always in practice—on more endogenous, participatory, human-centred models. More specifically, we can classify the theoretical underpinnings in the history of approaches to development into three broad perspectives or paradigms: (1) Modernization theory, which grew out of Western thinking on development in the immediate postwar period; (2) Dependency theory, which gained prominence in the 1970s as an aggressive critique of the modernization approach primarily from a Southern perspective; and (3) the most recent “Multiplicity” or alternative cultural pluralist approaches that have emerged since the 1980s (Akhahenda 2004; Houston and Jackson 2009; Melkote 2002; Servaes 1999, 2004, 2008; Thussu 2006). These evolving theoretical perspectives on development have likewise been accompanied by changing notions of both the role and the method or mode of communication in the development process, characterized by a general shift from a focus on mass media and diffusion to an interest in grassroots participation and dialogical processes. However, it is important to note that despite the historical context in which these paradigms emerged, no one approach has replaced its predecessor in theory or in practice, and they continue to operate concurrently (Houston and Jackson 2009; Servaes 1999). As we shall see in the sections that follow, by charting the history of these changing development paradigms and communication theories embodied in different Communication for Development

approaches over the past fifty-plus years,<sup>25</sup> we can discern marked dichotomies and tensions which have emerged along several key fault lines: emphasis on process versus product; dialogical versus transmission models of communication; diffusion of information and innovations versus participation and indigenous knowledge sharing; bottom-up and endogenous development versus top-down and exogenous approaches.

### *2.1.1 Modernization Theory*

Following the Second World War, a distinct gap became evident between rich, rapidly-growing industrial nations and Third World countries mired in poverty and ‘underdevelopment,’ and questions surfaced as to the role wealthy countries should play in the development of their poorer counterparts (Nyamnjoh 2006). With the United States’ involvement in the Marshall Plan<sup>26</sup> and the corresponding growth in confidence in the role of economic aid overseas, the imperative for American involvement in international development was firmly established. In his inaugural address in 1949, US President Harry Truman proclaimed:

We must embark on a bold new program for making the benefits of our scientific advances and industrial progress available for the improvement and growth of underdeveloped areas. More than half the people of the world are living in conditions approaching misery... I believe that we should make available to peace-loving peoples the benefits of our store of technical knowledge in order to help them realize their aspirations for a better life. (qtd in Binns 2008, 81)

As Western theorists sought to explain the ostensibly quantifiable differences between ‘rich’ and ‘poor’ countries in the 1950s and 1960s, and to propose the best measures for poorer states to ‘catch-up’ to the ‘advanced’ nations in the West, modernization theory emerged as

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<sup>25</sup> For more in-depth discussions of this history than I will be able to provide here, see Servaes 1999, 2004 and Thussu 2006; for an African perspective, see Akhahenda 2004.

<sup>26</sup> It is important to note that the Marshall Plan—a program of immense US financial support for the reconstruction of Western Europe following the war—was simultaneously a ‘goodwill gesture’ and a self-serving program designed to stimulate markets for the American manufacturing sector (Binns 2008). International development has continued to exhibit this underlying tension: altruistic motivations have been dialectically offset by particular political and economic interests, such as the desire to bring newly independent states in Africa and elsewhere into capitalism and open the way for Western transnational corporations (Servaes 2008; Thussu 2006).



the dominant development paradigm amidst this flurry of optimistic research and policy development—indeed, the United Nations declared the 1960s the “decade of development” (Thussu 2006, 44).

Central to the modernization thesis is the distinction between ‘traditional’ and ‘modern’ societies. According to proponents of the thesis, some countries remain in a natural state of underdevelopment, and therefore must engage in a process of changing their ‘backwards’ attitudes and ‘traditional’ practices to become ‘modern’ (Nyamnjoh 2006; Servaes 1999). Western industrialized nations are held as the pinnacle of the development process, and underdeveloped states are exhorted to ‘catch up’ to this ‘ideal model’ (Melkote 2002; Servaes 2004). By contrast, the ‘laggard’ underdeveloped states are seen to be mired in systems of thought that can be qualified as ‘pre-scientific,’ ‘pre-logical,’ or ‘irrational,’ and hence modernization theory suggests they must embrace scientific rationality<sup>27</sup> and the modern knowledge, innovations, and technologies it has produced (Nyamnjoh 2006, 396). ‘Modernity’ here is inextricably linked with Western ideas of ‘progress’ that are deeply rooted in Enlightenment thinking; hence, in this view ‘development’ is perceived as a spontaneous, unidirectional, cumulative, predetermined, and irreversible evolutionary process, a series of universal stages<sup>28</sup> through which all societies must pass (Melkote 2002; Nyamnjoh 2006; Servaes 1999, 2004). This linear universal conceptualization of development is accompanied by an understanding of development defined largely in terms of economic growth, since modernization theory tends to focus on quantifiable economic and

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<sup>27</sup> Jacobson (2004) highlights debates on the nature of “ethnophilosophy,” which is the idea that African culture embodies a unique system of thought. While he supports African participation in knowledge creation to guide development, he rejects ethnophilosophy research that suggests African indigenous thought can be characterized as “emotive” in comparison to the privileged “rational” Western thought. He perceives such arguments to be a dangerous construction of the Other—an African instance of Said’s Orientalism.

<sup>28</sup> American economist Walt Rostow’s (1960) model of unilinear stages of economic growth was highly influential on development thought, bringing with it the dual assumptions that there is one universal model for economic development and that all countries will imitate the Western experience. Rostow also shared modernization theory’s emphasis on the central role of technology in driving growth.

industrial indicators of social advancement, rather than the human needs, desires, and contentment of citizens in these ‘traditional’ societies<sup>29</sup> (Akhahenda 2004; Binns 2008; Unwin 2009).

Modernization theorists contend that to successfully become a ‘modern nation,’ traditional states must adopt the political and economic structures, institutions, attitudes toward technology and science, and cultural mores and practices of Western industrialized nations (Melkote 2002, 421). Central here is the idea that the West, having already passed through these stages, can help guide and expedite this process by ‘transferring’ knowledge, attitudes and, crucially, technologies. As modernization is seen to be congruous with industrialization, the transfer of technology, industrial and economic systems, and socio-political culture is perceived to be pivotal in accelerating the transformation from tradition to modernity (Servaes 2004). Hence, the transfer of ‘technical knowledge’ highlighted by Truman in his inaugural address embodied a central aspect of the modernization approach; Western nations were seen as ‘experts’ with valued knowledge and technologies to be transferred, the underdeveloped countries in the Third World were portrayed as passive recipients of this technical assistance.

According to modernization theorists interested in the role of communication in this process, mass media were seen as ideal agents for facilitating this transfer, by spreading awareness of new possibilities, practices, and attitudes, and persuading recipients to adopt these new ideas and innovations in order to accelerate the process of modernizing their societies (Melkote 2002; Servaes 1999). From a modernization perspective, there was a need to change indigenous knowledge, attitudes, and behaviour in order to change economic and

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<sup>29</sup> Binns (2008) suggests that modernization theory can be more appropriately classified as an “economic growth” model than a “development” model.

social institutions. Influential theorists like Lerner<sup>30</sup> (1958), Rogers (1962), and Schramm (1964) advocated that the vehicle of mass communication had a crucial role to play in this process of change. Through exposure to media, these societies would be less bound by tradition, as citizens would aspire to new ways of life, abolishing traditional ‘backwardness’ by forsaking attitudes, values, and beliefs that were obstacles to modernization, and embracing those which would propel transformation (Thussu 2006, 43). This idea that media could transform individuals and societies in the developing world was rapidly embraced and further explored and refined by other theorists. In the years following Lerner’s study, the burgeoning field of communication and development was marked by a proliferation of research and discussion on: the role of mass media as “magic multipliers” that could magnify and accelerate the benefits of development (Schramm 1964); the specific processes of the diffusion and adoption of innovations (Rogers 1962); the roles of mass media and interpersonal communication in these processes; and the effectiveness of various techniques of persuasion<sup>31</sup> (Bessette 1996; Melkote 2002; Mody 2002; Servaes 1999, 2008; Singh 2002; Thussu 2006; Waisbord 2001).

The modernization/diffusion approach to Communication for Development has been widely critiqued for its top-down, one-way, ‘transmission’ view of communication, which privileges exogenous ideas and solutions over local knowledge and beliefs, focusing only on the information flow from Western ‘modern’ nations to ‘traditional’ recipients (Jacobson 2004; Nyamnjoh 2006; Saik Yoon 1996; Servaes 1999). It is this deeply ethnocentric nature of much postwar development thinking—perceiving the path to ‘modernity’ in universalist,

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<sup>30</sup> Lerner’s (1958) study of development and communication in the Middle East was a pivotal moment in the history of Communication for Development; since their advocacy by Lerner, communications media and techniques have been employed as strategic interventions in development (Mody 2002; Singh 2002).

<sup>31</sup> These theorists were heavily informed by media effects theory and US interwar propaganda research (Melkote 2002; Nyamnjoh 2006). This interest in mass communication as a vehicle for persuading individuals in the Third World to adopt modern ideas and innovations inspired two important paradigms for health communication in a development context—behaviour change communication and social marketing—which I will discuss further in Chapter Three, specifically in relation to HIV/AIDS health communication.

‘one-best-way’ terms based on the Western experience and denying the possibility of other, perhaps preferable, development paths—which has resulted in modernization often being regarded as a veiled synonym for ‘Westernization,’ with media and communication perceived as insidious conduits for the spread of Western ideas, values, technologies, and practices without regard to the needs and desires of local people (Akhahenda 2004; Binns 2008; Melkote 2002; Nyamnjoh 2006; Servaes 1999, 2004; Shade 2003; Thussu 2006). This ethnocentric nature of modernization theory has resulted in the failure of many projects, due to the flawed assumption that results from the West can be extrapolated to the Third World with little consideration of particular local contexts (Servaes 1999, 30; Singh 1999, 202).

Modernization theorists’ negative view of ‘traditional’ culture, and their corresponding focus on the need to change individual attitudes and beliefs, rather than broader structures—what has been critiqued as a tendency to ‘blame the victim’—meant a failure to account for the complex realities in developing nations: “The dominant paradigm, with its exaggerated emphasis on the individual blame causal hypotheses regarding underdevelopment, obfuscated the social structural, political, and institutional constraints acting against individuals’ efforts to change” (Melkote 2002, 432). This was compounded by the technologically determinist conception of mass media as a determining agent of change in development, with a direct causal link between media as ‘magic multipliers’ and positive development outcomes (Houston and Jackson 2009, 107; Servaes 2004, 60). Moreover, not only is modernization theory’s rigid dichotomy of ‘tradition’ and ‘modernity’ ethnocentric and unrepresentative of the complex nature of the diverse societies around the globe, but it also, troublingly, serves to deny citizens in these so-called ‘underdeveloped’ nations their humanity, their agency, their human potential. Instead, they are positioned merely as ‘backward’ people in ‘primitive’ places; passive targets to be persuaded to adopt ‘good’ and

‘proper’ attitudes, knowledge, institutions, and practices. However, as Nyamnjoh has eloquently argued in the case of African development, “Africans are actively modernizing their indigeneities and indigenizing their modernities, often in ways not always obvious to scholarly fascination with dichotomies” (2006, 393).

This recognition of human agency and self-determination—lacking in modernization theory—is crucial to development, particularly in postcolonial Africa. Asante (2004) argues the need for an Afrocentric orientation to be incorporated into any Communication for Development initiative in Africa. He defines Afrocentricity as “an intellectual orientation toward viewing Africans as subjects of history with their own agency in the midst of all phenomena” (2004, 5). He suggests that adopting an Afrocentric approach to Communication for Development theory and practice demands the positioning of Africans as actors, rather than spectators, in the development process, as agents of change centered within a historical context, capable of determining their own needs and possibilities. Such a perspective is not possible within the top-down, ethnocentric, diffusion models of modernization theory, and this limitation has been a source of criticism of this dominant paradigm from the African continent and elsewhere.

### *2.1.2 Dependency Theory*

Although it was criticized globally from many different theoretical perspectives, some of the strongest and most aggressive early critiques of modernization theory originated from Latin America in the late 1960s and early 1970s, as a number of scholars questioned its false assumptions and premises, and raised new questions about the relationship between communication, power, and knowledge (Servaes 1999, 26; Thussu 2006, 46). The modernization approach to development had failed to deliver any perceptible improvement in the lives of the world’s poorest communities, and many argued that not only was it

inadequate and unsuccessful in transforming lives, especially in Africa, but it had actually produced greater inequalities, contributing to even more suffering (Briggs 2008, 107; Conway and Heynen 2008, 93).

Dependency theory offered an alternative explanation for the global disparities between developed and underdeveloped countries: underdevelopment is a direct product<sup>32</sup> of the capitalist expansion of the West, and hence the Third World is not in a natural state of poverty and underdevelopment as a result of its backwards customs, philosophies and practices, but rather because of the unequal nature of international relations (Dos Santos 1970; Servaes 1999; Thussu 2006; Waisbord 2001). Dependency theorists contend that development in the West creates and maintains a relationship of dependence for the impoverished nations of the Global South occupying peripheral positions in the world economic system. The concentration of economic and political power in the West—and the reproduction of socioeconomic and political structures in the periphery in accordance with the interests of powerful centre nations—ensures continued imperial dominance and maintains the underdevelopment and the political, economic, and cultural dependency of the Third World (Servaes 2004, 57). Dos Santos explains:

By dependence we mean a situation in which the economy of certain countries is conditioned by the development and expansion of another economy to which the former is subjected. The relation of interdependence between two or more economies... assumes the form of dependence when some countries (the dominant ones) can expand and can be self-sustaining, while other countries (the dependent ones) can do this only as a reflection of that expansion. (1970, 231)

So long as nations remain on the periphery of economic activity, they remain locked into a relationship of dependent development, and meaningful autonomous development therefore remains impossible without structural change in the global economic system (Akhahenda

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<sup>32</sup> Andre Gunder Frank (1969) refers to the “development of underdevelopment” to suggest these conditions are two facets of the same process—underdevelopment is the flip side and consequence of Western development—and must be understood in the context of the world system rather than in isolation.

2004, 119). Whereas the modernization approach targeted more individual behaviour change and the dissemination of information and innovations, dependency theorists are explicitly concerned with these broader social factors and structural constraints, suggesting it is this misplaced focus and neglect of these socio-structural conditions which has resulted in much of the failure of development programs<sup>33</sup> (Waisbord 2001).

In reaction to the ahistorical, apolitical, and ethnocentric facets of modernization theory, dependency theorists argue that development is not a matter of overcoming internal problems (traditional attitudes, practices, etc.) but of surmounting external obstacles to development imposed by the structural inequalities of the present international economic system<sup>34</sup> (Bessette 1996; Servaes 2004). This perspective is informed by neo-Marxist and critical macro political-economic approaches and locates the root causes of underdevelopment in the political history of colonization and the ways in which newly independent states have been integrated into the global economic system, attributing the problems of underdevelopment to capitalist development and the corresponding unequal international distribution of resources (Conway and Heynen 2008, 92-3; Dos Santos 1970, 235; Thussu 2006, 47; Waisbord 2001).

Dependency theory engendered new perspectives on both ‘development’ and ‘communication’ and the relation between them. Dependency theorists explicitly rejected the linear universalist conceptions of development and the Eurocentric models of modernity central to modernization theory. Development was instead perceived as a process to be

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<sup>33</sup> This perspective persists in contemporary critical development literature, and some scholars continue to find the dependency paradigm a relevant analytical framework for explaining various paths to development and underdevelopment, noting the many areas of development where dependency continues to play a significant role, such as “aid dependency, technological dependency, dependency for foreign capital investment, trade dependency, dependency for better human capital formation and so forth” (Ghosh 2001, 133).

<sup>34</sup> Dependency theory has been frequently critiqued for placing too much focus on this international level of analysis—the lack of internal state and class analysis within the periphery affords little attention to national and local contradictions and the ways in which development structures serve the interests of internal centres in developing countries themselves—and misdirecting political action in some instances as a result of this overemphasis on political factors (Bessette 1996; Houston and Jackson 2009; Servaes 1999, 42-44).

stimulated and determined endogenously at the national level, a process that may be realized differently in different nations as they disassociated themselves from the unequal global market and pursued self-reliant and self-determined development strategies (Besette 1996; Servaes 2004, 58). Although development here continued to be viewed in rather economic terms by many dependency theorists, the socio-structural and intensely political emphasis meant that in many cases development was defined as political struggle (Servaes 1999, 31). With respect to communication, the ‘dependistas’ recognized that modernization’s promise of mass media’s potential to foster development had failed to deliver, but their diagnosis was not that this dissemination of Western ideas and innovations had failed in the act of persuasion (Rogers and Hart 2002). Rather, since dependency theory identified the problem in political—as opposed to informational—terms, there was no deficiency in local knowledge to be overcome, and hence the premise of modernization’s diffusion thesis was inherently flawed (Waisbord 2001). Thus, for dependency theorists, mass media carrying foreign messages cannot serve as agents of positive social change and development because they transmit Western and capitalist ideologies. In fact, communication can serve as a basis to new forms of imperial domination<sup>35</sup> (Besette 1996; Thussu 2006). This asymmetrical, one-way flow of communications and socio-political culture, it was feared, would impose Western values and cultural practices at the expense of local cultures, which may be destroyed, with disastrous implications for the future development of these nations. As Nyamnjoh laments,

The implication for African countries of taking their political, cultural, economic and intellectual cues from the West as modernisation theorists suggest, is the risk of losing any political autonomy, cultural identity, economic independence and intellectual creativity that they may have. Yet...these very qualities are the necessary preconditions for development in tune with the expectations, dignity and humanity of Africans. (Nyamnjoh 2006, 398)

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<sup>35</sup> See Schiller (1969, 1976) for discussions of this “cultural imperialism” thesis.



Hence, amongst the broader socio-structural and political changes called for by dependency theorists were arguments for the reformation of media and communication to promote indigenous cultures and endogenously-determined national and public goals which would serve local citizens, rather than capitalist ideologies and development objectives as determined by external Western actors<sup>36</sup> (Waisbord 2001).

### 2.1.3 *Multiplicity*

Although less clearly defined and coherent than the modernization or dependency paradigms, we can broadly identify a third approach to Communication for Development that comprises a collection of critiques of the two earlier perspectives and proposes alternatives based on cultural pluralism and grassroots participation. Jan Servaes (1999, 2004, 2008) has called this the “multiplicity” paradigm, characterized by alternative approaches that view both communication and development as multidimensional processes. It emphasizes cultural identity, empowerment, and pluralism, responding to the widely acknowledged inadequacy of the earlier paradigms and the complex socio-political and cultural realities of an increasingly globalized and interconnected world, in which modernity/tradition, centre/periphery, and the First/Third World labels are too narrow and simplistic to represent the plurality of relations, identities, interdependencies, and contexts for ‘development.’ While particular definitions and methodologies within this multiplicity umbrella are varied, we can identify important commonalities in the way Communication for Development has been framed by their advocates.

Inherent in this multiplicity perspective is a stern critique of the dominant way development has been defined, framed and implemented, particularly by modernization

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<sup>36</sup> This perspective led to calls to correct the structural inequalities in international communication and establish a New World Information and Communication Order (NWICO) in the 1970s (Thussu 2006, 31-39).

theorists. In contrast, it offers a reconceptualization of the nature of development to afford more fluid and pluralistic understandings. Proponents of this alternative culturalist approach deny the concept of one universal path to development, perceiving instead a multiplicity of development paths just as there is a multiplicity of diverse cultures worldwide. They therefore argue that “development must be conceived as an integral, multidimensional, and dialectic process which can differ from one society to another” (Servaes 2004, 58). Rather than a set series of stages that can be dictated from an external source, every society should pursue endogenous development, finding its own definition of development, and establishing its own objectives and strategies (Nederveen Pieterse 2010, 96-97; Servaes 1999, 6; White 2004, 9). Dissatisfaction with mainstream development in the 1970s led many critics to call for “Another Development,”<sup>37</sup> that would be alternative, people-centered, context-specific, and bottom-up—very much the antithesis to the modernization approach (Nederveen Pieterse 2010, 85; Saik Yoon 1996; Servaes 2008). In this view an alternative development “could be defined as need-oriented, endogenous, self-reliant, ecologically sound, and based on participatory democracy and structural transformations” (Servaes 1999, 6). This conceptualization of development is very much focused on ‘human’ development: whereas modernization theorists had defined development in terms of economic growth, framing development in a socio-political and cultural vacuum and failing to ask questions about who would benefit or how wealth would be distributed and used for the public good (Thussu 2006, 44), proponents of ‘another’ development demanded not only that these non-economic variables be considered, but that they become the *priority*. Development is defined primarily

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<sup>37</sup> This term was most notably first articulated by the Dag Hammarskjöld Foundation in Sweden, in its 1975 report “What now? Another development,” which called for the reimagination of development practice. The report identified three ‘pillars’ of another development: it should be “geared to the satisfaction of needs,” “endogenous and self-reliant,” and “in harmony with the environment” (Dag Hammarskjöld Foundation 1975, 28). Moreover, the report explicitly identified that this alternative form of development requires transformation of socioeconomic and political structures for the benefits of development to reach the most impoverished communities (37-39).

in cultural terms, with the people and communities who are to benefit situated at the centre, and empowerment identified as an important goal (Quarry and Ramírez 2009, 21; Thioune 2003, 10; White 2004, 10).

Adopting these principles and perspectives of development yielded new forms of communication and new conceptualizations of the role of communication in the development process. Echoing calls for ‘another’ development were appeals for ‘another’ communication model: such “alternative communication” would be democratic, participatory, decentralized, socially horizontal, and “rooted in the masses who are currently marginalized by a communication system that serves the preponderant interests of the transnational corporations and the dominant internal economic and political power groups” (Nyamnjoh 2006, 406). Such visions of “emancipatory communication” necessitated re-conceptualizing communication as an active process—rather than mere passive reception—in which “the flow of communication would no longer be one way; instead, it would flow in many different directions, thus making empowerment a possibility for the disenfranchised” (Wong 2001, 3). In contrast to the top-down, one-way transfer of messages in the diffusion model, simply disseminating information from (Western) ‘experts’ to ‘ignorant’ audiences, this alternative model would be based on understanding and multidirectional communication (Waisbord 2001, 18).

Such a crucial distinction between ‘information’ and ‘communication’ has not often been adequately acknowledged in mainstream development discourse. As Quarry and Ramírez explain, development organizations and practitioners tend to see communication as “the transfer of information from one group of people to another... Yet communication and information are not the same. This is not theoretical hair-splitting: it is a substantial distinction between sending information in different formats, and people exchanging ideas

and values through dialogue” (2009, 14). Effective communication involves more than the act of transmission in a linear process of information delivery—it involves ‘listening’ as well as ‘telling’—and hence those arguing that information is of little value without communication have suggested that what is truly needed is the participation of traditional ‘receivers’ in the communication process (Quarry and Ramírez 2009; Servaes 2004, 61; Unwin 2009, 61-62). Participation, in this sense, is understood as the basis for genuine communication.

This emphasis on understanding and participation also implicitly critiques the tendency of modernization and dependency theorists to depict audiences as passive recipients with little agency to interpret, modify, and use information and media products in different ways in accordance with their own cultural values and contexts. Hence, the notion of ‘participation’ is of central importance in many alternative culturalist approaches to Communication for Development, and is now increasingly recognized as the basis of many aspects of sustainable development (Bessette 1996; Cole 2008; Saik Yoon 1996; Servaes 1999, 84-8). “Participatory development communication...aims to support people’s participation in their development by enabling groups and communities to diagnose the problems they face, make well-informed decisions, mobilize for action, and assume responsibility for their own development” (Bessette 1996). This emphasis on endogeny and self-determination is not only attuned to the principles of ‘another’ development, it also advocates grassroots participation and mobilization, and is integral to citizen and community empowerment.<sup>38</sup> This is an important aspect of many participatory approaches, and the emphasis placed on the exchange of ideas and values in the creation of shared meaning is

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<sup>38</sup> Empowerment can be defined as a process of enhancing community members’ individual and collective identities and motivations for self-improvement: “Empowerment is the affirming of the dignity and value of one’s own identity and re-evaluation of the local culture. It also means resignifying the cultural institutions so that one’s own cultural capital is given greater recognition and is seen as more valuable” (White 2004, 21).

particularly compatible with an Afrocentric orientation to communication for development on the continent. In listening to local needs, knowledge, and conditions, such dialogical communication processes demonstrate respect for traditional values and modes of communication, deferring to local cultural subjectivities, experiences, identities, capabilities and social, cultural, economic, and political contexts for development (Akhahenda 2004, 119-20; Jacobson 2004, 70; Servaes 2004, 61). In its emphasis on dialogicity and grassroots empowerment, the participation movement clearly emphasizes communication *processes* over *products*—for example, supporting the facilitation of community discussions on the barriers to family planning, rather than producing a billboard or radio program advocating condom use—and many proponents have argued that participation should be supported as both an end in itself and as an integral part of the development process<sup>39</sup> (Houston and Jackson 2009; Melkote 2002, 428; Waisbord 2001, 20). As Quarry and Ramírez argue in their recent assessment of the field of Communication for Development, “*Another Development* provided the stage for good communication. It follows that *participatory communication shapes the very nature of development, while ‘telling’ communication simply promotes the desired development outcome*” (2009, 141, emphasis in original).

## 2.2 ICT4D: Modernization Resurrected?

Although in theoretical discussions the ‘multiplicity’ and other alternative cultural pluralist approaches to Communication for Development have enjoyed growing prominence, the reality remains somewhat different in policy and practice. Indeed, “there is something of

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<sup>39</sup> Participatory development models have been widely critiqued, especially within the field of anthropology, noting the issues of cost, sustainability, inclusivity, continued local power differentials, and frequent failure to achieve its set objectives of bottom-up processes of emancipation. For example, Saik Yoon (2006) has suggested that we should problematize this rather idealistic and vaguely defined notion of participation. He suggests that four different types of participation can be identified in development projects claiming to be participatory in nature: *implementation* (citizens are encouraged and mobilized to be involved in implementing projects); *evaluation* (citizens provide feedback on projects); *benefit* (citizens enjoy positive outcomes of a project); and *decision-making* (citizens are directly involved by initiating, discussing, conceptualizing and planning projects which they will then execute as a community). Saik Yoon argues that decision-making is by far the most important of these in fostering genuine empowerment and sustainability; and asserts that the other three forms may be criticized as “false participation,” often serving merely as ideological masks to hide the real power structures at work.

an impasse between critical academic writing on development, and the policies adopted by global agencies charged with eliminating poverty” (Unwin 2009, 14). Even though modernization is no longer theoretically dominant and its tenets are increasingly difficult to defend, revised versions of the paradigm persist (especially in policy and practice, but also in academia). The ethnocentric, paternalistic beliefs and economic outlook upon which it is built are still, arguably, shared by many governments, development agencies and practitioners, corporations, and the majority of Western public opinion (Servaes 2004, 64). Despite the acknowledged inadequacy of the diffusion model, in many cases the top-down, information-dissemination approach to communication in development contexts prevails, contributing to the failure of many well-intentioned projects (Unwin 2009, 68). This disconnect between theory and practice speaks both to the enduring persuasive influence of the modernization perspective (often referred to now as neo-modernization or modernization 2.0), and to the difficulty of implementing alternative approaches with genuinely participative and process-oriented modes of communication within the mainstream development industry (McAnany 2010; Quarry and Ramírez 2009).

However, a number of critics have pointed to a notable difference in the way modernization narratives have been resurrected or kept alive in the past decade or so:

In a revised version of modernization theory, a shift has been detectable from support for the mass media to an almost blind faith in the potential of the new information and communication technologies...According to this view, modernization requires advanced telecommunications and computer infrastructure, preferably through ‘efficient’ private corporations, thus integrating the South into a globalized information economy. (Thussu 2006, 46)

Indeed, there has been great—often exaggerated—emphasis on the significance of the so-called ‘information revolution’ or ‘information age’<sup>40</sup> we currently find ourselves in, and on the need for developing countries to propel themselves into the global ‘information society’

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<sup>40</sup> See Manuel Castells’ (2000a, 2000b, 2004) extensive trilogy on the subject, *The Information Age*.

through the adoption of new and rapidly evolving ICTs (Mosco 2004, 18; Unwin 2009, 19). Even for the world's most impoverished countries, embracing the "Information Society" is "unquestionably perceived as a chance... to blend into a world of economic opportunities and social well-being," and ICTs are widely accepted as ideal vehicles for these countries to use to surmount their persistent marginalization (Alzouma 2005, 339-340). As a result, influential international institutions such as the World Bank and the United Nations<sup>41</sup> have emphatically argued the need for developing countries to embrace ICTs in order to foster development, and there has been an intense push by multilateral and bilateral organizations, development agencies, national governments, and civil society groups to get 'wired' or otherwise 'connected.'<sup>42</sup>

Arguments about the modernizing potential of mass media seem to have been recycled and reimagined in the discourse surrounding the supposedly 'revolutionary' potential of new ICTs to catalyze development; moreover, these narratives have often reappeared with renewed vigor as ICTs are often attributed the exceptional ability of enabling countries to 'leapfrog' or accelerate their pace of development and connect with global markets<sup>43</sup> (Colle 2008; de Beer 2004; Heeks 2002; Leye 2007; Nederveen Pieterse 2010; Schech 2002; Wilson 2003). We can thus see elements of modernization theory underpinning many ICT4D narratives, not only in the conception of development as a series

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<sup>41</sup> In 1997, the UN General Assembly endorsed the "right to communicate" as a human right with a declaration on the aim of universal access to basic communication and information services, positioning the introduction and use of ICTs as a top priority to secure sustainable development (Colle 2008, 141; de Beer 2004, 158).

<sup>42</sup> Notable high-level examples include the 1996 launch of the *infoDev* (Information for Development) program at the World Bank, the establishment of the G-8's Digital Opportunity Task Force in 2000, the UN 2001 "ICT Task Force," and the 2001 decision of the New Partnership for Africa's Development (NEPAD) to focus in part on identifying and enhancing digital opportunities for African nations (Shade 2003; Unwin and de Bastion 2008). A more recent example is Nicholas Negroponte's One Laptop Per Child project (<http://one.laptop.org>).

<sup>43</sup> The 'leapfrogging' thesis is not new, and this is not the first time technologies have been promised as means of overcoming perpetual problems faced by developing nations (Alzouma 2005, 341; Singh 2002). The notion of 'leapfrogging technologies' dates back several decades to arguments for the liberalization, privatization, and expansion of telecommunications: "The phrase 'leapfrogging development' reflects the belief, especially in the 1980s, among policy makers and theoreticians that information technologies, especially telecommunications, can help developing countries accelerate their pace of development or telescope the stages of growth" (Singh 1999, 4-5).

of unilinear stages inherent in this ‘leapfrogging’ thesis, but also in the continued importance of Western technology (Thussu 2006, 46) and in the emphasis on the ‘knowledge’ or ‘information’ economy and its promise for developing countries, “which is based on the assumption that a deficiency in knowledge is partly responsible for underdevelopment” (Schech 2002, 13). The mainstream view of ICTs as a conduit of information still predominantly involves transmitting privileged Western knowledge rather than creating and sharing local knowledge (Leye 2007, 987). This continued ethnocentric conceptualization and valuation of certain types of knowledge is perhaps the most blatant persistence of modernization theory in ICT4D discourse and practice, and the result is invariably the disqualification or devaluation of local knowledge<sup>44</sup> (Schech 2002, 20; Wilson 2003).

However, the promotion and use of ICTs in development has not been limited solely to a modernization agenda, and hence it is too simplistic for us to cynically dismiss ICT4D as mere resurrection of that much-criticized enduring paradigm. The reality is much more complex, and indeed ICTs may offer substantial contributions to foster ‘another’ development—and democratize communication processes in development to achieve ‘another communication’. As Unwin argues, “ICTs are equally significant in these alternative development agendas, and have the potential to play an important role in enabling the emergence of new forms of political organisation and social movements” (2009, 15). This is particularly true of newer ICTs that, in their very design, afford greater potential for two-way or grassroots communication.<sup>45</sup> Thus, we must continue to critically examine ICT4D

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<sup>44</sup> As a result, questions as to “whose knowledge counts?” remain one of the most central and contentious issues in development discourses related to ICTs and the information/knowledge economy, and many writers have advocated the importance of actively incorporating indigenous knowledge into the conception, design, and implementation of development projects in order to achieve appropriateness, effectiveness, and sustainability, although this is too seldom the case in contemporary mainstream development practice (Briggs 2008; Nymanjoh 2006, 394; Schech 2002, 11, 18; Wilson 1999, 63).

<sup>45</sup> The democratizing and empowering aspects of the Internet, for example, have been widely discussed, as proponents have noted the potential for this technology to facilitate participatory, bottom-up and multi-directional communication and to document local knowledge, in addition to its amplification of broadcast media’s ability to disseminate information to mass audiences (Melkote and Steeves 2004, 167; Singh 2002, 490).



discourse and practice in order to unpack underlying assumptions and theories, unravel the ahistorical and apolitical myths imbued in much techno-centrist discourse, account for the duality of transmission-oriented models existing alongside more participatory modes of engagement, and uncover the genuine promise that does indeed exist.

### **2.3 A Critical Look at ICT4D: Promises, Pitfalls, and Possibilities**

The expectation and assumption that ICTs and the ‘Information Society’ are essential to social and economic development is now pervasive in mainstream development literature and practice. New advances in ICT have been accompanied by promises to enhance well-being, education, and liberty, positively transforming lives and empowering citizens around the globe (Alzouma 2005; de Beer 2004; Thioune 2003; Unwin 2009). For developing countries, these technologies have been heralded as a way to ‘level the playing field,’ overcome geographic, social, and literacy barriers, and reach many people simultaneously and efficiently, while reducing the cost of sending and receiving information (Cole 2008, 144; Heeks 2002; Leye 2007, 973; Selwyn 2004, 342). As a result, ICTs have been frequently proclaimed as holding significant potential for numerous aspects of development, presenting developing countries with opportunities in areas as diverse as economic growth, governance, education, health, democratic engagement, and environment sustainability<sup>46</sup> (Alzouma 2005, 341; Rice 2009, 123). Indeed, in mainstream policy and academic discourse these technologies are often conceived as a panacea:

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<sup>46</sup> Unwin (2009) suggests that we can distinguish between two general types of promises about the potential of ICTs, based on two different understandings of development: development as economic growth, versus development as participation, empowerment, and meaningful benefits for poor people and marginalized communities. He believes that ICTs can theoretically play a key role in delivering both, but that while there are strong arguments that ICTs can contribute to development when it is defined exclusively as economic growth, using ICTs to foster holistic and human-oriented development has proven more challenging, as dominant interests and uses of ICTs have often enhanced inequalities and detracted attention from potential uses that benefit the most marginalized. For example, increased proliferation of ICTs also means increased opportunities to commoditize information and communication—much to the benefit of the powerful neoliberal interests that propound the revolutionary significance of these technologies. Yet, commoditized information and communication contributes to further knowledge divides, and potentially increased economic inequality as well, and the promotion of ICTs as ends in themselves distracts from the importance of harnessing these technologies for empowerment, inclusion, and positive social change.

ICT has the potential to accelerate growth, create jobs, reduce migration pressure from rural to urban areas, increase agricultural and industrial productivity, increase services and access to them, facilitate the diffusion of innovations, increase public administration efficiency and the effectiveness of economic reforms, strengthen competition in developing countries, and encourage greater public participation and democracy. (von Braun and Torero 2006, 1)

Particularly in rural areas—in Africa and elsewhere—ICTs are promoted as especially promising for economic and social development, with proclaimed benefits including the enhancement of business opportunities and efficiencies,<sup>47</sup> the facilitation of rural and ecotourism, increased access to health information and services; the expansion of educational opportunities (such as distance learning); and enabled communication between friends and family in previously isolated locales (Melkote and Steeves 2004, 166).

Despite the enormous potential of ICT4D, the intense enthusiasm and hype that has accompanied it “has often been exaggerated and misplaced” (Unwin 2009, 360). The beneficial development outcomes so ardently promised by the proponents of ICTs are “not sustained by clear evidence when it comes to how these technologies will perform the miracle” (Alzouma 2005, 341). Rather, it seems that this omnipresent idea that ICTs will lead to development is supported intuitively. The benefits are held to be true axiomatically, even though they have not been delivered in a meaningful way in most development contexts, on the African continent or elsewhere, and that there remain a number of critical limitations impeding the full realization of the promised benefits (Leye 2007, 972; Thioune 2003, 2). This continued optimism and ‘blind faith’ in the promise of ICTs reveals the incredible power and cogency of ICT4D narratives in contemporary mainstream development discourses. Therefore, as many writers have argued, it is imperative that we pause to assess

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<sup>47</sup> Much has been made of the market benefits of ICTs for rural areas, such as the potential for easier location of markets and supplies, arranging for delivery of supplies and raw materials, rapid acquisition of information such as market prices, carrying out financial transactions, and empowering rural traders in negotiation of prices. However, less consideration has been given to negative effects of ICTs in these contexts (such as the opportunity costs associated with prioritizing ICTs over other services, or increased social or economic inequalities that result from their use, especially along gendered lines) or to the challenges the rural poor face in realizing such benefits (including high costs, weak infrastructure, or access barriers, as discussed below) (Melkote and Steeves 2004).

the prevalence and seductive allure of these narratives—critically examining the underlying assumptions of these ICT4D discourses, and situating them in both historical and political contexts (Leye 2007, 972, 979; Schech 2002, 13; Wilson 2003). In examining the limitations of mainstream policy and academic approaches to ICT4D, we can identify the following critical considerations: the shortcomings of technocratic or techno-utopian visions of ICTs and progress, the need to problematize the concept of ‘access,’ and the political economy implications of ICT4D policy and interventions.

### *2.3.1 Progress, Technomania, and ICT4D*

We can begin to examine the limitations of ICT4D by scrutinizing this mythic aspect of mainstream discourse on ICT4D and the information society, and historicizing the rhetoric of technology as an agent of radical change and a ‘magical’ fix in a long sequence of narratives equating technological advancement with progress. Much of the mainstream development discourse and practice can be characterized by an intensely “techno-centric perspective,” in which “ICTs represent a revolutionary force that can fundamentally transform societies and individual lives. In this perspective, the imperatives of technological development determine social arrangements: technological potential drives history” (Hamelink 1997, 23). This inclination toward technological determinism and viewing technological innovation as inherently progressive is, of course, not a new phenomenon. Technology has been at the heart of Western thinking on development for centuries, part of a long tradition of seeking solutions to all the world’s ills in technological breakthroughs. Such ardour is deeply rooted in the Enlightenment notion that technology can ultimately free humanity from all natural and social constraints (Alzouma 2005, 351; Schech 2002, 19; Singh 1999, 203; Unwin 2009, 9). One technological innovation after another has been introduced into society, each one heralded as a revolution; each accompanied by promises of

“social transformation and social betterment” (Mosco 2004, 139). Eventually, the process of technological innovation itself came to be perceived as social progress, conflating advancements in technological development with advancements in socio-political development.<sup>48</sup> This technocratic view of progress converts the development problem into a technical one, with negative implications for the realization of meaningful improvements in people’s lives (Singh 1999, 204).

This techno-utopian perspective on the inherently progressive and emancipatory nature of technology is unhelpful in any meaningful analysis of the potential impact of ICTs on development. These myths about technology—seductive promises of revolution and liberation—promote a vision of the “technological sublime”<sup>49</sup> so powerful that it induces a widespread historical amnesia (Mosco 2004, 117). The same intense hype that animated the spread of earlier technologies is now circulated in mainstream discourses propounding the benefits of ICTs. Contemporary discussions and debates about ICTs and development tend to exhibit strong ahistorical tendencies, demonstrating little attention to—or understanding of—previous technology-related development discourses and initiatives (Heeks 2002, 1; Leye 2007, 979; Pickard 2007, 118). Particularly in developing countries, the contemporary promotion of ICTs is not the first time a new technology has been championed as a means of accelerating social change and overcoming chronic development barriers: tractors, electrification, and broadcasting were, in their own times, lauded as holding the same grand potential that is now afforded to ICTs (Alzouma 2005, 340; Mosco 2004, 119).

Mosco insists that we must avoid this ‘technomania’—so often present in mainstream

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<sup>48</sup> This perspective is evident in modernization theory’s focus on the diffusion of Western technological innovations to developing nations—‘technology transfer’ was the imperative, with little emphasis on access, skills, or meaningful use of these technologies (Leye 2007, 978-979; Shade 2003, 114-115).

<sup>49</sup> Mosco defines the technological sublime as “a literal eruption of feeling that briefly overwhelms reason only to be recontained by it” (2004, 22). He notes Leo Marx’s (1964) description of the rhetoric of the technological sublime as hymns to progress that rise “like froth on a tide of exuberant self-regard sweeping over all misgivings, problems, and contradictions” (qtd in Mosco 2004, 23).

ICT4D discourse—with its ahistorical promises of overnight radical change (2004, 21). While new ICTs are frequently described in development discourses as revolutionary, unprecedented, and bound to ‘change everything,’ they should instead be viewed in the historical context of an evolving continuum of technological innovation (Heeks 2002, 3). Ignorance of this historical context—including the critiques that have been launched against development approaches like modernization—contributes only to the hegemony of a narrow, ahistorical, techno-utopian conception of technology’s role in development, which succumbs to technological determinism, ascribing to new technologies the ability to change fundamental socio-political structures, simply by their material existence (Alzouma 2005, 347; Leye 2007, 979).

This techno-utopian, techno-deterministic perspective has met with much disagreement and critique, particularly in development contexts (Shade 2003, 107). The past fifty years of scholarship on communication and development has been “informed by a dialectic of technology as a panacea versus its effects being circumscribed by the social, political, and economic contexts in which it is introduced” (Singh 2002, 493). According to critics, the problem with perceiving ICTs as a ‘magic’ solution for developing countries is not only that it is ahistorical, but that it is largely apolitical: “A technical solution to underdevelopment is provided without regard for the complex political forces at play and developing countries are implored to participate in the new information society that has been stripped of its political attire” (Wilson 2003). Presenting ICTs as a panacea for development draws attention away from social and economic inequalities, allowing the political factors influencing poverty and inequality at local and global levels to be obfuscated—or at least go largely unnoticed—and ignoring the complex interplay of other socio-cultural and economic constraints shaping the uses and implications of these technologies (Melkote and Steeves

2004, 171; Wilson 2003).

Moreover, mainstream ICT4D discourse tends to construct these technologies as neutral tools, severed from political, economic, socio-cultural and institutional contexts. As applications of knowledge, technologies are, however, themselves cultural constructions, embedded with certain types of knowledge and cultural values from which they originated (Heeks 2002, 5; Wilson 1999, 58-9). Indeed, “the gravest problem with the techno-centric perspective is that it ignores the social origins of information and communication technologies. It suggests that they originate in a socio-economic vacuum, and fails to see the specific interests that generate them” (Hamelink 1997, 23). Likewise, the particular socioeconomic and political contexts, and the specific interests of human actors involved in determining the ways in which ICTs are used, are equally important in influencing the meaning of these technologies. The technology itself actually plays a rather ambiguous role in development—it is not the inherently emancipatory force foretold by the techno-utopian ICT4D myths, nor the necessarily pernicious influence some techno-pessimists may suggest. Thus, we must not consider the issues surrounding the use of ICTs in development solely in the technical sphere, but also in the larger socio-political realm which gives them meaning, examining the ways in which ICTs are shaped by their external social conditions of both production and use (Alzouma 2005, 347, 351; Singh 1999, 213; Thioune 2003, 2).

### *2.3.2 Understanding the ‘Digital Divide’: Theorizing Access*

At its most basic level, the concept of using ICTs to propel development is a paradigm which presupposes that the availability of, and access to, ICTs will automatically lead to development; as a result, access has been one of the most debated aspects of ICT4D (Alzouma 2005, 342; Leye 2007, 978). However, these discussions have focused predominantly on quantitative rather than qualitative measurements or indicators of ‘access’:

the penetration rate of computers or telephone lines, the material presence of actual physical artifacts, and the proximity of the technologies in question to potential users (Alzouma 2005, 342; Selwyn 2004, 347). This has resulted in much of the discourse surrounding ICTs and development being dominated by considerable mainstream political discussion about the ‘digital divide,’<sup>50</sup> information and communication poverty, and the vast disparity between information ‘haves’ and ‘have-nots.’ “The prevailing political view broadly settled on combating a perceived dichotomous divide between those citizens who are ‘connected’ and those citizens who remain ‘disconnected’ from technology, information and, it follows, modern or postmodern society” (Selwyn 2004, 344). The very notion of the digital divide is thus based on an assumption of binary opposition deeply rooted in modernization theory: just as a sharp distinction was made between ‘modern’ and ‘traditional’ countries, the ‘information rich’ and the ‘information poor’ have been framed in similar terms, with the imperative being for the information poor to embrace modern communication technologies in order to ‘catch up’ (Shade 2003; Wilson 2003).

Both popular and political conceptualizations of this divide have tended to be composed in this strictly dichotomous fashion: “you either have access to ICT or you do not, you are either connected or not connected” (Selwyn 2004, 345). Against this oversimplified classification, the reality is more complex, and this ‘divide’ might, more usefully, be understood “as a hierarchy of access to various forms of technology in various contexts, resulting in different levels of engagement and consequences” (Selwyn 2004, 351). However, the more simplistic dichotomy carries strong rhetorical appeal: its straightforward definition makes it seem correspondingly straightforward to combat issues of access. This allows for the “neat packaging of complex social issues in a form of social exclusion that governments

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<sup>50</sup> This term was introduced in the 1990s to refer to the growing disparities in access to computers and the Internet (see for example Norris 2001).

can be seen to do something about, unlike more longstanding and fundamental ‘non-digital’ divides” (Selwyn 2004, 357). If the problem is merely a lack of the physical presence of technologies, then this is a relatively easy development obstacle to overcome, particularly in comparison to more nuanced conceptualizations of universal access to equitable means of communication and information sharing. This ‘haves versus have-nots’ perspective is intricately related to techno-centrist and techno-determinist approaches that position the use of ICTs—defined here as ‘access,’ or more appropriately, geographical proximity to the technologies—as an end in itself, rather than as a means of achieving broader development objectives, as though the mere physical presence of technology or infrastructure would in itself contribute to achieving the MDGs (as discussed in Chapter One) (Heeks 2002, 6).

This fascination with the digital divide begets a deeply misleading discourse, and constructs a limited framework for ICT4D analysis, because the focus on digital or technological divides detracts attention from other divides that are often more significant impediments to development (Heeks 2002, 7; Nederveen Pieterse 2010, 167; Selwyn 2004, 343-345; Wilson 2003). “The disadvantaged remain disadvantaged because of the divides and inequalities in a broad range of resource endowments—knowledge, skills, money, power and others—regardless of whether they can access data using ICTs” (Heeks 2002, 8).

Mainstream development discourses have constructed the digital divide as a major unequalizing force in the global economy—rather than locating the blame for global inequalities in international political and institutional structures—and hence narrowing the digital divide is positioned as a crucial step in achieving global goals to reduce poverty (Leye 2007, 978; Rice 2009, 123). As Leye notes:

This not only obscures the fact that the digital divide may more accurately be just a reflection of the socio-economic or development divide between ‘developed’ and ‘developing’ countries... It also suggests that when the developing world finally is adequately and sufficiently connected, it will become fully integrated into the global



economy and hence become an equal partner of the rich countries. (Leye 2007, 978)

This implication is far removed from any geo-political reality, as it ignores the fact that developing countries are indeed already integrated into the global economy, under unjust and inequitable global trade laws that favour developed nations, and which arguably are significant contributing factors to digital and non-digital divides in the first place (Leye 2007, 978; Wilson 2003). Without consideration of political and socioeconomic contexts, ICT4D discourses about ‘bridging the digital divide’ and achieving ‘universal access’ become completely apoliticized, concerned with the technical matters of when and how to ‘connect’ communities in the global South, rather than with discussion on who should connect, for what purposes, under what conditions, and with what implications for societal betterment (Nederveen Pieterse 2010, 167; Shade 2003, 109, 113). In this context, the very notion of the digital divide can be considered fundamentally apolitical.

It is not that these ‘digital divide’ discourses are entirely misplaced or mistaken. There are certainly profound disparities in access to ICTs, both between developed and developing countries and within countries themselves, along, for example, class, gender, literacy divisions (Alzouma 2005; Rice 2009). Particularly in African contexts—but also elsewhere, especially in rural areas—these material barriers to accessing ICTs can be insurmountable, both on individual and collective levels: geographic isolation and lack of widespread fixed infrastructure means that the time and costs associated with use are often prohibitive<sup>51</sup> (Melkote and Steeves 2004, 170; Unwin 2009, 82). Moreover, gender remains a

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<sup>51</sup> For example, a number of ICT4D-oriented development projects have focused on establishing telecentres or cybercafés to bring computers and Internet use to marginalized isolated or poor communities, yet the cost of use remains out of reach for many, and access can be slow and unpredictable due to the inadequacy or scarcity of broader infrastructure (phone lines, electricity, etc.) and other unanticipated factors—for example, the extent to which service is inhibited by theft of copper cable is a problem in many poor countries (Colle 2008, 146-8; Melkote and Steeves 2004, 166; Unwin 2009, 92-94). This is a frustration I have personally experienced living in a peri-urban African community, and simply illustrative of the complex web of social and economic factors influencing ICT access that are not easily accounted for in penetration-style statistics.

significant barrier, as women's access to ICTs is disadvantaged, especially in Africa,<sup>52</sup> but also in other developing regions and in northern countries (Buskens and Webb 2009, 2; Melkote and Steeves 2004, 170; Thioune 2003, 47; Unwin 2009, 28). Yet most popular understandings or measurements of the digital divide fail to account for these more nuanced aspects. What is sidelined in such techno-centrist mainstream digital divide discourses is any discussion of *meaningful* access to and use of communications technology. It is clear that we cannot bridge these divides or address these disparities merely by enhancing the spread of infrastructure and the physical presence of technology in the world's most marginalized communities. Thus what is needed is for access to be defined more comprehensively, encompassing considerations of what is required for ICTs to benefit and be used by marginalized populations in meaningful ways, and not simply to reproduce or enhance socioeconomic inequality, as has sometimes been the case (Alzouma 2005, 342; Thussu 2005, 235; Unwin 2009, 30). Such a comprehensive understanding of access necessitates moving beyond reductive discussion of penetration rates or physical proximity to technology, and taking into consideration the political, economic and socio-cultural constraints that limit use of ICTs<sup>53</sup> (Alzouma 2005, 344; Selwyn 2004, 347; Thioune 2003, 59-79; Wilson 2003; Wong 2001). "Simply ensuring that all people have ICTs within walking distance for example does not mean that these people will have the required education and skills, financial resources and other factors required to make use of the technology and so to have access to the information provided" (Wilson 2003). Nor does it ensure that citizens will have the desire to use these technologies, and that the content and connections available to them

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<sup>52</sup> In an excellent collection of research on ICT4D from a gender perspective in Africa, Buskens and Webb (2009) argue that the relation between African women, their empowerment, and their use of ICTs is complex, because—although on the whole women both contribute less to the information society and benefit less from it—on the African continent ICTs can empower and enhance the lives of women, but can also exacerbate gender inequality.

<sup>53</sup> This perspective also inherently critiques the technologically determinist conflation of technology with people's capacities to receive, process, and transmit information using this technology (Melkote and Steeves 2004, 169).

will enhance their lives in a meaningful way.

Beyond these technical, economic, skills, literacy, and gender-based barriers to use, to be truly accessible, information produced and obtained through ICTs must be socially and culturally relevant. It must be transferrable, in a meaningful way, to the actual reality of the user. Arguably, much of the information available through ICTs is not appropriate for many users in developing countries, language being the most obvious reason (Alzouma 2005, 344; Selwyn 2004, 347; Wilson 2003). Therefore, Selwyn argues that it is of critical importance not to conflate “access to ICT” with “use of ICT”:

This presumption is at the heart of conventional notions of the digital divide and is reinforced by the determinist belief that access to ICT inevitably leads to use... Similarly, use of ICT does not necessarily entail ‘meaningful’ use where the ‘user’ exerts a degree of control and choice over the technology and its content, thus leading to a meaning, significance, and utility for the individual concerned. (Selwyn 2004, 348-349)

Likewise, Wong suggests that we can distinguish between two ways of viewing access—access as ‘availability’ and access as ‘participation’—both are needed in order to achieve “true communicative access” (Wong 2001). In many cases, the first type of access is rapidly being accomplished. ICTs are being proliferated at an ever-growing pace and are already a part of the broader context in many of even the poorest and most marginalized communities. Mobile phones are on the forefront of this in many regions, as I will discuss later. The question is therefore not a matter of whether these populations should have this technology made available, but the extent to which this second, more holistic, understanding of access will be achieved. What remains to be seen is whether ICTs in this context will be another point of inequality and disenfranchisement, or whether they will be realized as a meaningful catalyst for social change and empowerment (Unwin 2009, 30).

### 2.3.3 *The Political Economy of ICT4D: New Development Opportunities, or Merely New Markets?*

While, as we have seen above, holistic conceptualizations of access are scarce, another critical consideration which is also inadequately addressed in mainstream ICT4D discourse and practice is an examination of the macro political and economic forces at work in this push to use ICTs as a vehicle for development. Critiques that examine the political and economic contexts within which technologies are developed, distributed and promoted have been particularly strident with respect to ICT4D and the information society. From the start, dominant ICT4D policies and practices have been established on a model heavily reliant on private enterprise,<sup>54</sup> conceptualized as a process of government and business working together to expand both markets and development opportunities (Singh 2002, 492). From this perspective, ICT4D can be understood as a neoliberal vision of corporate-enabled emancipation. This is exemplified by the way ICTs are addressed in the MDGs, one of the most important high-level documents influencing international development and poverty alleviation initiatives in the past decade. Although ICTs are specifically referenced, and the ICT4D notion is clearly endorsed,<sup>55</sup> “it is crucial here to emphasize that ICTs are mentioned explicitly in the context of private-sector involvement in development partnerships” (Unwin and Bastion 2008, 56). In fact, this private sector involvement in information- and communication- based development initiatives can more broadly be seen as a part of the general rise in neoliberal approaches to development—what has been called the “corporatization” or “marketization” of development—where private firms came to replace

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<sup>54</sup> This is an area of critical consideration for mHealth initiatives in particular, with their heavy dependence on transnational cellular corporations, which I will address explicitly in Chapter Five.

<sup>55</sup> Goal 8 of the MDGs is “Develop a global partnership for development,” and one of its targets is: “In cooperation with the private sector, make available benefits of new technologies, especially information and communications” (UN 2010, 66, 71). Access to ICTs here is, notably, still measured in terms of penetration rates of telephone lines, mobile phones, and Internet users as opposed to more comprehensive measures of access, or analysis of ICT use and whether the “benefits” of these technologies are indeed being “made available,” as outlined in the target.

the state as key agents in development<sup>56</sup> (Leye 2007, 973; Schech 2002, 16).

The implications of development partnerships with the private sector have not been adequately examined or addressed in mainstream ICT4D discourse, and many critics—perhaps most notably Manuel Castells—castigate the particular private interests involved in promoting ICTs in development contexts, asking questions about who it is that actually benefits most from ICT4D (Hamelink 1997, 23; Unwin and Bastion 2008, 55). These critics suggest that private-led ICT4D initiatives must be interpreted as developments in the rise of networked capitalism, and hence fundamentally incompatible with the emancipatory promises that have accompanied ICTs: the spread of these technologies are subject to the power structures and transnational flows of capital, and will generally prioritize capital needs over local needs, benefitting the transnational ICT corporations disproportionately (Leye 2007, 973; Nederveen Pieterse 2010, 170; Singh 2002, 492). Rather than perceiving networked ICTs as something radically new and liberating, critical scholars “point out the business-as-usual aspect of these new information networks,” whose primary function “is that of sustaining and coordinating global financial, production, and distribution flows”—not freeing the poor from their socioeconomic oppression, as some techno-enthusiasts may have us believe (Singh 2002, 491). According to this perspective, the dramatic expansion of ICTs and the push for ICT4D has been driven not primarily by altruistic motivations to improve the lives of poor and marginalized populations, but rather by the interests of the private sector, eager to expand and deepen their markets, and reduce labour costs (Unwin 2009, 32; Unwin and Bastion 2008, 55-56). This is a highly strategic aspect of ICT expansion:

ICT4D is digital capitalism looking south—to growing middle classes, rising

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<sup>56</sup> Pickard (2007) notes that this ascendance of neoliberalism in approaches to development is reflected by the current policy focus on technical issues. He suggests that there was a notable shift in rhetoric from the overtly politicized debates around NWICO in the 1970s, which focused on communication rights and called for structural changes, to the recent discussions at the World Summit on the Information Society (WSIS) in 2003 and 2005, which were largely ahistorical, apolitical, and focused on the technical aspects of the information society.

education levels, vast cheap labour pools, and yet difficult regulatory environments. It is about *market expansion* and converting unused capacity into business assets on the premise that new technology is the gateway to hope. And it is about the *deepening of the market* by pressing for liberalization, opening up spaces for competition and investment, bypassing regulations or devising new regulations that will shape the future. (Nederveen Pieterse 2010, 173)

This conceptualization of ICT4D anticipates limited possibilities for the marginalized, as the process is not designed for their benefit. As opposed to endogenous, human-centred, locally-owned, participatory projects, “...the new technologies are embedded in capital and as such they evoke development from above; most public-private partnerships around ICT are typically too technical and capital-intensive in nature to be participatory” (Nederveen Pieterse 2010, 175). Moreover, the technologies themselves, designed in many cases for consumers in rich markets, may not be appropriate for poorer populations, so while their introduction may help meet market pressures, they may not be put to the best use for social betterment (Thioune 2003, 144).

Many facets of these political economy critiques of ICT4D echo dependency theory, but perhaps the most marked continuity is the related concern—particularly enunciated by critics on the African continent and elsewhere in the global South—on the role ICT4D is playing in perpetuating technological dependency (Leye 2007, 981; Nederveen Pieterse 2010, 169). Eribo (2004), for example, has vigorously cautioned against uncritical celebration of the spread of new communications technologies such as mobile phones on the African continent, because their invention and development have been mainly outside of Africa, and thus their proliferation is establishing a new technological dependency that may lead to degeneration, not development. Therefore, he argues that the focus for ICT4D proponents should be on stimulating domestic research rather than consuming foreign products at the expense of indigenous industries, and that, at a theoretical level, the adoption and diffusion of these communication technologies should be re-examined within the framework of what he

calls the “creative mindset paradigm” for development in Africa (Eribo 2004, 178-182).

Eribo describes the tendency to measure African development through material quantification and datasets (such as the number of mobile phones) as falling within the “consumption paradigm,” since they are more accurately indicators of the consumption of foreign products than indications of development. The “creative mindset paradigm,” by contrast, is interested in the indigenous development, use and implementation of such technologies, and in recognizing Africa’s creative capacities for innovation, technological advancement, and endogenous development initiatives. Although Eribo seems to lament the lack of local innovations and contributions in this respect, there are indeed a number of remarkable indigenous ICT4D initiatives underway on the continent, especially based on mobile phones, as I will discuss in greater detail in Part Two of this thesis.<sup>57</sup>

## **2.4 On Orchids and Opportunities: Some Final Thoughts on ICT4D Implementation**

The preceding critiques are not intended to indiscriminately dismiss the potential benefits of ICTs as powerful tools to be leveraged for social change, but rather to underscore the critical imperative of nuancing the promises of greatness with some awareness of the pitfalls, and of contextualizing ICTs and their use in development within historical and political contexts, before (cautiously) celebrating the opportunities that may unfold. Indeed, many communication for development practitioners and scholars, myself included, hope that ICTs will continue to be embraced as an important element in communication-centric and general development initiatives, and that we will continue to ask under what circumstances ICTs can effectively foster development-related aims. However, it is essential to realize that their greatest potential lies in approaching them not as a panacea, but as a somewhat

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<sup>57</sup> A prominent example is M-PESA, a mobile banking service that was pioneered in Kenya and exported to Tanzania and Afghanistan. Other notable innovations include the Mxit platform, a free instant-messaging chat application for mobile phones, and the “Please Call Me” (PCM) technology. I will explore mHealth applications of these innovations in Chapters Four and Five.

ambiguous instrument, one that can both empower and contribute to greater inequality, depending on the social, political, economic, and cultural contexts of use. Wendy Quarry and Ricardo Ramírez, two long-term practitioners in the field of Communication for Development, liken effective communication projects to prize orchids: too often, we focus on the flower, fascinated by the sublime beauty of the bloom without noticing the conditions which enabled it to flourish in the first place (2009, 61-62). In ICT4D, conditions such as the politics, the institutional contexts, the local culture and history, the media environment, the individuals involved, the structures of funding and implementation are the basis of success, yet too often our focus is on the particular technologies chosen or on the ‘best practices’ to be replicated elsewhere. If a pilot is successful, it is expected to be scaled-up for universal success and multiplied results, but in many cases there is inadequate examination of the ways in which the project changes in each new context. You would not transplant a prize orchid to a completely new environment and expect it to thrive; you would pay close attention to the local conditions and the needs of that environment, and plant a locally-appropriate variety, tailoring the soil, water, and temperature to the local requirements. Perhaps upon careful analysis you would learn that the local environment would not benefit from an orchid at all, that other plants might be better-suited. This careful consideration and local adaptation—from the very start of project conceptualization and design—is what is critically needed for ICT4D to be successful, since the one-size-fits-all, top-down, ‘best practices’ approach is inherently flawed (Unwin 2009, 363-4). Unfortunately, this need is frequently obscured by the mythic aspects of apolitical and ahistorical techno-utopian discourses.

The challenge, both in discourse and in practice, is to strike a balance between techno-utopian and techno-pessimistic perspectives, and remember that, in many ways, “the technology is actually secondary to the process” (Wong 2001, 22). The potential for ICTs to



contribute positively to development depends on much more than the technical artifacts themselves—complex political, economic, and socio-cultural factors unavoidably shape the use, meaning, and impacts of these technologies—which is why careful consideration of local contexts is so important, and why ICTs only makes sense when they respond to needs (Quarry and Ramirez 2009, 101; Unwin 2009, 76, 363). Hence, strong emphasis should be placed on selecting appropriate technologies for the local context, rather than focusing first on the technology itself (Nederveen Pieterse 2009, 177; Unwin 2009; 364). Any review of the recommendations for best hopes of success as found in critical literature reveals that there is some agreement that examining the context for ICTs in any development initiatives—the local needs, conditions, gender relations, economic factors, socio-structural barriers, and existing technologies, infrastructure and communication practices—is not sufficient. We must also develop a socially-led ‘moral’ or ‘ethical’ agenda or framework for ICT4D in order for the promised benefits of ICT to be realized in marginalized communities (Leye 2007; Unwin 2009). Such an approach would be based on “a combination of freedom of expression, knowledge, democratic principles and the concept of justice” (Leye 2007, 980). Similarly, Heeks has argued that while common approaches to ICT4D tend to either *ignore*, *isolate*, or *idolize* ICTs, what is required is “an *integrated* approach...[that] sees ICTs as a means to an end, not an end in themselves” (2002, 6). Against techno-centrist proclamations of the benefits of “e-development,” he calls for i-development: “The approach to ICTs must be information-centred, integral to its environment, integrated with development objectives, intermediated, interconnected, and indigenized. Above all, it must be intelligent” (Heeks 2002, 10).

Thus, while the limitations of mainstream ICT4D discourse and practice presented here are important, we must allow these critiques to guide the realization of more effective

and human-centred applications of ICTs in development context, rather than to cynically dismiss the potential of these technologies as mere ideological hype and utopian rhetoric. In discussing the promise of any ICT4D initiative, we must nuance grand claims of potential social change with a careful delineation of the necessary preconditions and priorities for the benefits of the technologies to materialize for marginalized populations—foregrounding the challenges and complexities of the opportunities presented—while emphasizing the importance of holistic, endogenous, participatory, bottom-up, dialogical, context-specific approaches.

## **2.5 Mobile Phones: Rethinking ICT4D in the African Context**

When considering the contexts for ICT-based development initiatives in Africa, and especially the matter of ‘appropriate’ technology, it becomes clear that the growing prevalence of mobile phones in this region demands a careful re-examination of the potentialities and nature of ICT4D on the African continent. Mobile telephony is radically changing the communications landscape in many regions of the world—the reach of mobile phones is far greater than any other communication technology in the past, with a global penetration rate of 87% (ITU 2011b). In the past ten years a growing body of literature<sup>58</sup> has noted that the impact of this technology is particularly significant in the developing world (especially in Africa), where mobile phones are being used to reshape the lives, livelihoods, and communication practices of citizens and communities in profound and unprecedented ways. Mobile telephony is rapidly being integrated into development and social change initiatives, especially in Africa and Asia, and by 2008, 86% of NGOs globally were using mobile phones in their work (Kinkade and Verclas 2008, 6; see also [mobileactive.org](http://mobileactive.org)). Much of the mainstream discourse around mobile telephony closely follows the same techno-

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<sup>58</sup> For an extensive review of literature on mobile phone use in developing countries, see Donner 2008.

utopian narratives discussed above. Some even suggest that “the digital divide that really matters then, is between those with access to a mobile network and those without” (The Economist 2005). Mobile telephony is widely considered to be important for development, and the rapid uptake of mobiles in developing nations, particularly in Africa, has caught the attention of both mass media and policy makers, who have suggested we are witnessing a narrowing of the digital divide in these countries (Donner 2008b, 29; Gray 2006; James and Versteeg 2007, 117; McGuigan 2005, 50). Yet, as above, rather than simply dismissing these echoes of technomania, we must contextualize this technology, examine the potential presented by its unprecedented ubiquity, and consider the extent to which various barriers to meaningful access inhibit or enable the use of mobile phones relative to other ICTs.

Perhaps the most visible and remarkable aspect of mobile telephony in the context of African development is the sheer prevalence and rapid spread of this technology on the continent. Exceeding all predictions, sub-Saharan Africa has a faster growth rate than any other region in the world, as mobile penetration has grown from just five per cent in 2003 to 53% at the end of 2011, with significant potential for continued exponential growth (Gray 2006, 1; ITU 2009, iii, 2011b). Penetration already exceeds 50% in the majority of African countries,<sup>59</sup> and in Botswana, Gabon, Namibia, Seychelles, and South Africa, there are actually more active mobile phone subscriptions than there are citizens<sup>60</sup> (ITU 2011b, 2012). In comparison, the Internet—although certainly offering great potential for new spaces of multidirectional, grassroots, participatory communication—remains largely irrelevant in the communication contexts of most Africans. Access remains marginal, with less than 13% of African citizens using the Internet in 2011, and only a fraction of these accessing high-speed

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<sup>59</sup> There remains great variance in mobile subscription rates between African nations, despite the deep penetration in many states. In 2011, Ethiopia, Burundi and Eritrea had only 17, 14, and 4.5 mobile subscriptions per 100 inhabitants respectively. South Africa, Botswana and Seychelles had 127, 143 and 146 per 100 inhabitants respectively (ITU 2011b).

<sup>60</sup> By way of comparison, there are 75 mobile phone subscribers per 100 Canadians (ITU 2011b).

broadband services (ITU 2011b).<sup>61</sup>

In the most impoverished nations, and those mired in persistent conflict or political instability, the prevalence of mobile phones is creating new channels of communication that were not previously available due to the scarcity of fixed line infrastructure. This appears to be where the most marked impact is evident (Unwin 2009, 105). In the Congo, for example, there are 391 mobiles for every fixed telephone line; in Liberia, the ratio is 615:1, and even in comparatively wealthier or politically stable states like Nigeria and Tanzania, the ratios are 133:1 and 159:1, respectively (ITU 2011b). This dramatic differential between fixed and mobile telephony speaks both to the systemic lack of communications technology infrastructure prior to the introduction of mobile telephony—and the corresponding latent demand for communications services (Srivastava 2008, 23)—and also to the important impacts that mobile phones are having on the communications contexts of these countries.

Proponents of mobile telephony often declare the near-universal coverage of mobile networks. In 2011, 90% of the global population had access to mobile networks, including the vast majority of those in remote rural areas and those in low-income countries (ITU 2011c). Although this is a necessary precondition to mobile phone usage, it tells us little about the true accessibility of these networks in terms of affordability and other social barriers (James and Versteeg 2007, 120). As noted above, we cannot assess the significance of mobile phones solely in terms of these quantified measures of access or technological penetration, since we know that these indicators can be misleading and can potentially conceal significant, persistent barriers to access and usage. James and Versteeg (2007) suggest an important clarification can be made between mobile phone subscribers, mobile

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<sup>61</sup> Moreover, Nederveen Pieterse has suggested that Internet-based development policy and initiatives follow “a Starbucks approach to ICT4D,” because in most development contexts “the emphasis on the Internet is inappropriate, reflects class bias and is inspired by commercial interests...the Internet is principally a middle-class medium...it presupposes literacy and the ability to absorb or create content and digital literacy” (2010, 177).

phone owners, those who have access to technology, and those who benefit from usage. Yet, the only data readily available is the number of subscribers, which is provided by the mobile phone companies, and since this term is used somewhat vaguely, it may be reported in different ways, depending on the operator's objectives and interpretation (James and Versteeg 2007, 118; Sutherland 2008, 2). Moreover, these statistics do not account for usage—almost certainly higher than subscription. Communal use of phones is quite common, particularly in the African context—either through sharing with friends, families, and neighbours or through entrepreneurial services such as the Grameen Village Phone Project in Bangladesh<sup>62</sup> or mobile phone kiosks—and hence it is difficult to estimate how many people are actually using mobile telephony<sup>63</sup> (Donner 2008b, 33; James and Versteeg 2007, 121; Srivastava 2008, 23; Unwin 2009, 81-82). It is also possible to subscribe to mobile telephony services without actually purchasing a handset, simply by using a pre-paid SIM card in other people's phones; hence, “the mobile phone penetration rates might be an overstatement of the actual number of phone owners, just as they are an understatement of the number of users”<sup>64</sup> (James and Versteeg 2007, 119).

Indeed, Sutherland (2008) reminds us that a figure of 100 percent mobile phone ownership is impossible: there will still be exclusion of the extremely poor, the disabled, people living in very remote areas, and those that are either too old, too young, or who elect not to use mobile telephony as a personal choice. Despite the celebrated high levels of mobile teledensity, this raises concerns about the forms of social exclusion that are concealed by such statistics (Sutherland 2008, 4). Rural areas still have less access to mobile phone

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<sup>62</sup> See <http://www.grameentelecom.net.bd/vp.html>

<sup>63</sup> At the same time, many people may have more than one subscription, either for business reasons (e.g. to rent out for clients to use) or simply to achieve cheaper rates of use by owning SIM cards for multiple networks and using the SIM for whichever network they are calling on, to take advantage of discounted service (Sutherland 2008). This complicates interpretation of these penetration statistics further.

<sup>64</sup> This has important implications for mobile-based ICT4D initiatives which presuppose being able to reach people on their personal mobile phones, as I will discuss in Chapter Five.

services, and for the poorest populations, the costs<sup>65</sup> remain significant, not only for call charges, but for handset ownership as well (Donner 2008b, 34; Srivastava 2008, 24; Unwin 2009, 106). Gender also continues to present a barrier to access—the gender gap persists in mobile phone usage in low- and middle-income countries, and in Africa, a woman is 23% less likely to own a mobile phone than a man<sup>66</sup> (GSMA 2010). Moreover, these statistics reveal little about the purposes for which these phones are actually used in developing countries; proponents have argued that mobiles naturally contribute to economic growth and make markets more efficient, but this technology is still mostly used for social purposes—not economic development (although these social benefits may well be more important) (Donner 2008b, 29; Unwin 2009, 106).

These simplistic measurements of access to mobile telephony, then, are insufficient in portraying the full social meaning and impact of this technology. Perhaps more helpful in analyzing the true ‘significance’ of mobile phones, in Africa or elsewhere, are the qualitative, in-depth studies which offer us insight into the meaning of these phones for marginalized or impoverished individuals and communities in the Global South, and hence help us to understand the true potential of this technology to contribute to development and empowerment.<sup>67</sup> In addition, to better understand and contextualize this technology, we need to ask *why* we have seen such dramatic proliferation of mobile phones in Africa, and identify the aspects of mobile telephony that are particularly well-suited for the African context.

Perhaps the most salient feature that has propelled the reach and significance of

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<sup>65</sup> We must remember that the cost of mobile phones, particularly in Africa, is not only economic. One of the most dire material consequences of the global proliferation of mobile is the issue of ‘conflict minerals’: some of the most important rare metals used in the production of mobile phones—coltan and tantalum—are mined in Central Africa, and are a source of civil wars over mineral rights, with the mining revenues funding continued conflicts and furthering human suffering in the area (McGuigan 2005, 46).

<sup>66</sup> Despite this gendered inequality in access it is important to also acknowledge the potential for gender empowerment deriving from women’s use of mobile phones, such as has been noted with Grameen’s “Village Phone” program (Donner 2008, 150) and similar African examples (Abraham 2009; Bantebya Kyomuhendo 2009; Meena and Rusimbi 2009; Sane and Balla Traore 2009).

<sup>67</sup> See Buskens and Webb (2009) for a collection of such in-depth, humanistic, qualitative case studies.

mobile phones in sub-Saharan Africa is the low cost associated with both the deployment of mobile networks—in part due to the greater suitability of wireless networks for remote and rugged terrain than fixed line infrastructure—and the use of mobile services by user communities (Srivastava 2008, 24). “For investors, mobile networks are often easier to deploy, operate and manage than conventional fixed lines, making wireless a logical business decision” (Gray 2006, 2). For users, mobile handsets and subscriptions are much more affordable than other communications technologies such as computers and Internet services. Particularly significant here has been the breakthrough of pre-paid subscription services, as opposed to contract-based services; this model appeals to people with lower or irregular incomes, since the use of services is not predicated upon having a bank account, physical or postal address, or financial resources to cover a fixed monthly fee (Gray 2006, 4; James and Versteeg 2007, 119; Srivastava 2008, 24). The popularity of this type of service—in 2008, 95% of sub-Saharan Africans subscribers were using prepaid service—has also spawned new forms of communication, and new services particularly tailored to local needs, such as the “Please Call Me” (PCM) message service which African mobile operators have established to allow customers who cannot afford to purchase any more airtime to get in touch with contacts for free<sup>68</sup> (ITU 2009, 17; Sutherland 2008, 9).

In addition to its affordability, the significance of the basic, person-to-person connectivity afforded by mobile telephony in isolated areas previously lacking fixed line infrastructure cannot be understated (Donner 2008b, 32). Not dependent on literacy, language, or technical skill (as may be the case with computers and the Internet), mobile phones are an immediate, personal, oral medium that allows people to connect with other individuals and organizations, information and, increasingly, services like banking or health care (Srivastava

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<sup>68</sup> See, for example, <http://www.vodacom.co.za/vodacom/services/Stay+in+touch/Please+Call+Me>

2008, 24-25). As both senders and receivers of information, mobile users are active communicators, creating new possibilities and channels for dialogical participatory communication in development contexts (Quarry and Ramírez 2009, 137-9).

In considering the significance of mobile phones in African development, there remains excessive techno-utopian hype, persistent barriers to meaningful access, and tensions regarding the critical dependence on the private sector—much the same limitations as with most other mainstream ICT4D discourse and practice. Yet, there is something particularly promising about this technology in the African context, because of its sheer ubiquity, low cost of use, and two-way communicative potential. This demands a re-imagination of the opportunities for ICT4D projects, policy, and practice in sub-Saharan Africa. What is most important here is to note that this potential is not about introducing new technologies or communications infrastructure—mobile telephony is already increasingly omnipresent in the lives of many Africans—but it is rather about harnessing this technology for good, and capitalizing on its reach to devise new and innovative Communication for Development initiatives that leverage the presence and appeal of mobile phones in the pursuit of meaningful development objectives. I will highlight a number of such initiatives specifically with respect to health objectives and mHealth applications, in Chapter Four. However, to understand how mHealth works in an African context, I will first provide some background on health communication and the largest health phenomenon in the continent: HIV/AIDS.



**--- CHAPTER THREE ---**  
**HEALTH COMMUNICATION AND HIV/AIDS:**  
**DOMINANT THEORIES AND ALTERNATIVE MODELS**

This chapter will focus on health communication as it applies to HIV and AIDS in a development context. I will examine the paradigmatic theories used in HIV/AIDS health communication, critiquing the focus—particularly in prevention-oriented interventions—on bio-behavioural models that tend to rely upon assumptions of ‘rational individuals’ and ‘reasoned action’ while neglecting broader socio-structural, demographic, and cultural factors that influence citizens’ vulnerability to infection. I will begin by discussing the socio-psychological behavioural theories that have been most influential with respect to AIDS-related communication initiatives, and suggest that while these approaches may in some cases begin to theorize the broader interpersonal or social epidemiological contexts shaping individual behaviour, they have nonetheless been employed primarily to target behaviour change at the individual level. I will highlight the way these theories have informed mainstream health communication approaches—commonly referred to as behaviour change communication—that have been pervasive in AIDS and development contexts, and critically discuss the mainstay “ABC” (Abstain, Be faithful, Condomize) model for HIV prevention. I will then explore the ways in which these dominant individual-oriented models of behaviour change are limited or problematic: they fail to adequately theorize the impacts of race, gender, class, and sexuality, and they do not fully account for the many aspects of broader social and physical environments that enable or constrain an individual’s ability to mitigate health risks or adopt preventive behaviours. Throughout this discussion, I will pay special attention to the limitations inherent in the application of these mainstream Western approaches in African cultural contexts, since disappointing results and project failures in many instances stem from reliance on inappropriate and often ethnocentric theories and models.

I will then contrast these dominant behaviour change communication paradigms with alternative approaches to HIV/AIDS health communication such as media advocacy, holistic ‘social determinants’ and culture-based models, and a human rights framework for health care. Moreover, I will also outline arguments for the inclusion of the *affected* as well as *infected* members of these African communities—especially women and girls—in designing and implementing communication strategies. I will suggest that rather than replacing individually-oriented behaviour change communication altogether, these alternative approaches should be taken alongside traditional models, shifting the focus from behaviour change to social change. Embracing a holistic multi-level strategy integrating biomedical, behavioural and socio-structural perspectives will necessarily involve actively developing context-specific, culturally-sensitive and dialogue-based frameworks for HIV and AIDS-related communication initiatives.

With respect to HIV/AIDS-focused health communication specifically, the emphasis has predominantly been on prevention and education, given the continued absence of either a cure or a vaccine to curtail the spread of the pandemic. However, in considering the paramount importance of the role of communications interventions in HIV/AIDS work, I will conclude this chapter by considering the need for communication-centric approaches not only to this prevention-oriented outreach—which no doubt remains a crucial aspect of AIDS intervention—but also to the full continuum of treatment and care programs, which have traditionally focused on biomedical models of support. I will argue here that communication has an indispensable role to play in this context, particularly in combating stigma, improving ART adherence, strengthening AIDS-related care and support systems, and fostering an enabling environment for positive living—all critical aspects of the broader spectrum of HIV and AIDS intervention.

### 3.1 Health Communication in the Era of AIDS

When AIDS was discovered to be a significant and growing health crisis in the early 1980s, the need for communication interventions to inform the public and help arrest the spread of the epidemic was already acute. Although the disease had initially been perceived to be confined to already-marginalized populations in the West,<sup>69</sup> it soon became clear that AIDS was spreading rapidly and that it presented a significant public health threat. By 1986, the World Health Organization confirmed that AIDS had reached global proportions—cases were reported in at least seventy-five countries—and contrary to previously conceived notions that it was a “gay disease,” AIDS was affecting women nearly half the time internationally, leading US Surgeon General Everett Koop to announce that AIDS was a potential threat to every person who was sexually active (Ratzan 1993, 2; Treichler 1999, 56-57). Yet in the first few years of the epidemic, little was known about the nature of the virus or its transmission, and hence most mass communication related to AIDS was characterized by hysteria, fear, discourses of blame, and stereotypical constructions of those affected (Treichler 1999; Whiteside 2008).

Once HIV was identified as the virus that causes AIDS, and more was understood about its modes of transmission,<sup>70</sup> the initial responses to combat the spread of the virus were mostly technical: distributing condoms, improving blood safety, and promoting safer drug

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<sup>69</sup> The US Centers for Disease Control (CDC) initially identified a “4-H list” of high-risk categories: haemophiliacs, homosexuals, heroin addicts, and Haitians (Treichler 1999, 20). Pope et al. suggest that ‘hookers’ could have been added as the ‘fifth H’ in this classification, given the emphasis traditionally placed on sex workers as the primary role assigned to women vis-à-vis HIV infection (2009, 2). Focus on such ‘high-risk groups’ characterized much of the early response to the epidemic—in the West and developing countries alike—and has been criticized as highly problematic. Not only does this emphasis on risk groups have the effect of further stigmatizing already marginalized populations, but it also misleadingly suggests that the dominant risk factor in acquiring AIDS is being a particular kind of person, rather than engaging in particular high-risk activities (Treichler 1999, 20). Moreover, as Treichler has noted, these ‘risk group’ categories often have little to do with the lived realities of human experience; for example, groups such as “sexual partners of injection drug users” do not share a self-defined identity, but rather exist as a collection of individuals with a shared characteristic of which some may not even be aware (1999, 218).

<sup>70</sup> HIV infection occurs when a bodily fluid carrying high enough quantities of the virus (blood, semen, vaginal or anal fluid, or breast milk) enters the blood stream, often through a mucous membrane. Although intravenous transmission (such as through the use of contaminated injection equipment) is more efficient, sexual transmission is by far the most common mode of infection: more than 80% of transmission worldwide occurs through sexual intercourse. Mother-to-child transmission can occur in utero, during birth, or through breast-feeding (Stine 2010; UNAIDS.org; Whiteside 2008, 28-9).

injection practices (Whiteside 2008, 3). While the biomedical<sup>71</sup> response to the epidemic focused on technical, biological solutions—thirty years later a cure for HIV remains elusive, development of microbicides has been disappointingly slow, and medical male circumcision (MMC) is as yet perhaps the closest thing to a vaccine—many public health agencies and researchers, local health service providers, and other AIDS support and advocacy organizations realized the critical need for communication to supplement these technical solutions in order to inform, persuade, and empower citizens to avoid risky behaviour (Auvert et al. 2006; Edgar et al. 1992; Ratzan 1993; Whiteside 2008, 36-38, 53). However, political leadership in the West was slow to react with coordinated national communication campaigns, arguably at least to some extent a result of prejudice, fear, and ignorance shaping directions of policy and research, as well as an unwillingness to directly and openly discuss the ‘taboo’ topics of sexual behaviour, drug use, and especially homosexuality (Treichler 1999). In the United States, President Reagan’s first public mention of HIV came in 1985, four years after the first discovery of AIDS, and it was several years after that before federal public health offices launched coordinated campaigns in mass media and national mailers to generate awareness and inform the general public of how to mitigate risks of infection<sup>72</sup> (Stine 2010; Whiteside 2008, 104-6). The most highly organized, articulate, compassionate, effective—and earliest—communication responses in developed countries came not from governments but from gay men, particularly in San Francisco and New York. Through the skilful use of informational materials and advertising on billboards, buttons, and leaflets,

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<sup>71</sup> The biomedical model of HIV prevention intervention focuses solely on biological facets of illness and behaviour, excluding psychological, social, and environmental factors as relevant determinants of health and illness, and positioning individuals as passive agents of their health (Mimiaga et al. 2009, 205). While this is an integral and necessary aspect of HIV and AIDS intervention, the biomedical approach will not be discussed here, as the focus of this thesis is on communication-based interventions.

<sup>72</sup> Notable examples include the 1987-1988 “America responds to AIDS” campaign with its series of public service announcements (PSAs) and the *Understanding AIDS* national mailer in the United States, and the British “Don’t Aid AIDS” campaign in 1986 and “Don’t Die of Ignorance” nationally distributed leaflet in 1987. While these campaigns aimed to educate the general public, subsequent campaigns specifically targeted designated “high-risk groups” (Noar 2009, 344; Salmon and Kroger 1992; Treichler 1999, 57; Whiteside 2008, 104-6).

close knowledge of their target audience, and tactful engagement of the media, gay communities in the West pioneered initiatives around ‘safe sex,’ and these education and awareness campaigns proved remarkably successful in fighting the epidemic in the early years,<sup>73</sup> leaving an important legacy for AIDS-related communication and advocacy initiatives (Morris and Dean 1994; Noar 2009, 344; Treichler 1999, 24; Whiteside 2008, 105).

From its initial discovery in Africa—where it commonly known as “Slim”—the epidemic evolved in a decidedly different way on the continent, marked by dramatically higher incidence rates, with the virus spreading more rapidly through populations as a whole, predominantly through heterosexual transmission<sup>74</sup> (Fuller 2008; Hooper 1990; Whiteside 2008). Although this necessitated a somewhat different communication response, for reasons I will address more closely below, the AIDS response in the West proved an important influence on African states; national health departments and development agencies in these countries have similarly focused on ‘risk groups’ such as truck drivers, migrant mine labourers, and sex workers, and continued to emphasize ‘tested methods’ and ‘proven interventions’ (Epstein 2008; Green 2003; Susser 2009). Yet, responses to AIDS on the African continent have also been profoundly shaped by complex postcolonial matters of race, identity, cultural tradition, and the complicated politics of international aid. This has engendered radically different communication responses among African nations—with varied levels of success—from the compassionate, open discussion and broad-based early intervention lead by the Ugandan government, to the denialist and delayed response in South

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<sup>73</sup> However, despite this early success, troubling recent epidemiological data suggests that HIV incidence has increased slightly in high-income countries in North America and Europe, whereas it has stabilized or decreased in many developing countries (UNAIDS 2009). This re-emergence of the epidemic is particularly evident among men who have sex with men (MSM): UNAIDS reports rising numbers of new HIV infections among MSM in Canada, USA, the United Kingdom, Europe, and Australia since 2000 (2009, 64-69).

<sup>74</sup> However, we must not overlook the presence of same-sex sexual relations in Africa, which have been rendered ‘invisible’ by many mainstream AIDS discourses, constraining and undermining interventions in troubling ways. Moreover, AIDS discourses have been used in some African nations as a vehicle of state-articulated homophobia and a moralizing cultural nationalism (Lowry 2008; Phillips 2004).

Africa (Epstein 2008; Feldman 2008; Patterson 2006; Susser 2009; Thornton 2008).

Just as the AIDS epidemic was emerging, so too was the field of health communication as an area of theory, research, and practice in its own right. Beginning in the mid-1970s, the term ‘health communication’ began appearing with increasing frequency in reference to a range of approaches to studying communication within health contexts. By the 1990s the field had evolved into a multidimensional discipline—incorporating scholars and practitioners not just from communication-related fields, but also from medicine, public health, psychology, sociology, management, education, and business—and it became a key contributor shaping public policy on the prevention of disease and the promotion of health (Lupton 1994, 56; Ratzan 1993; Rogers 1996; Wright et al. 2008). Throughout the 1980s, AIDS was most certainly a critical challenge for this emerging field. Yet, at the time—and even now, when at the close of the third decade of AIDS it remains one of the most pressing issues in global public health—it was not entirely clear what exactly was meant by ‘health communication’ or precisely what communication-based health interventions should look like. Health communication has variously been described as “human interaction in the health care process” (Kreps and Thornton 1984, 2), “the process and effect of employing ethical persuasive means in human health care decision making” (Ratzan 1993, 5), and “a key strategy to inform the public about health concerns and to maintain important health issues on the public agenda” (WHO 1998). Ratzan et al. offer a more comprehensive definition:

...health communication is defined as the art and technique of informing, influencing, and motivating individual, institutional, and public audiences about important health issues. Its scope includes disease prevention, health promotion, health care policy, business, as well as enhancement of the quality of life and health of individuals within the community. (Ratzan et al. 1994, 362)

This definition reflects the broad and diverse nature of health communication scholarship and practice. It encompasses many different communication contexts, forms, channels, and areas

of focus, from interpersonal relations between health professionals and patients to the design and evaluation of mass-mediated campaigns; from media advocacy to new media-based interventions (Fukuda and Ebina 2011, 174; Ratzan 2011, 109; Ratzan et al. 1994; Rogers 1996).

Despite the theoretically broad scope of health communication, some aspects (such as advocacy) have historically been under-emphasized, while a select few dominant socio-psychological theories and behaviour models gained prominence in the 1980s (Airhihenbuwa and Obregon 2000; Lupton 1994; McKee et al. 2008). These “classic health communication models have tended to focus on individual decision-making, and resulting interventions have emphasized sending one-way, expert, risk-based, generic messages to individual ‘receivers’” (Neuhauser and Kreps 2010, 14). This emphasis on transmission models of communication for influencing individual behaviour has profoundly shaped the manner in which AIDS awareness and prevention programs have been conceived and carried out around the world. Hence, to better understand the health communication response to AIDS over the past three decades, and the reasons why a somewhat different approach has been needed in sub-Saharan Africa, we must first examine these paradigmatic ‘behaviour change’ models, which originated in the West and have been applied to HIV/AIDS health communication interventions internationally with mixed results at best (Bertrand et al. 2006; Singhal 2003, 22; UNAIDS 1999, 6).

### *3.1.1 Models for Behaviour Change in HIV Prevention*

In the early years of the epidemic, many practitioners presumed that a lack of knowledge was largely responsible for risky AIDS-related behaviour—such as sharing injection equipment and engaging in unprotected sex—and thus that simply providing the public with accurate information about HIV transmission and modes of prevention would

lead people to cease high-risk activities, limiting the spread of the disease (McKee et al. 2004, 41; UNAIDS 1999, 5). This mistaken assumption that information alone would result in behaviour change—an assumption that lingers implicitly in some interventions today—proved naïve, as many people continued to engage in behaviours associated with great risk despite having acquired knowledge and awareness about HIV and AIDS (Epstein 2008, 126; McKee et al. 2004, 41; Quarry and Ramírez 2009, 108). Research has proven repeatedly that while knowledge is a necessary condition for changing behaviour, education alone is not sufficient to induce behaviour change in most instances; a knowledge-behaviour gap exists where increased knowledge about HIV does not translate directly into decreasing rates of infection (Freimuth 1992, 106; Okigbo et al. 2000, 100; Snyder 2007, 34; UNAIDS 1999, 5).

Intervention planners increasingly realized that behavioural change is a complex multi-dimensional process that occurs through changes in perception, motivation, and attitudes, and that individuals need not only information, but also the skills and desire to apply such information (Fukuda and Ebina 2011; McKee et al. 2008, 254; Michal-Johnson and Bowen 1992, 166). In this sense, HIV prevention is not exclusively—or even primarily—a problem of transmitting knowledge, but rather one of changing attitudes and behaviour; in other words, it is a motivational rather than an informational challenge (Rogers 2000, 2). Practitioners soon recognized that the challenge in designing effective interventions, then, was not only to identify the knowledge ‘gaps’ or ‘insufficiencies’ and ‘bad’ behaviours—the knowledge, attitudes and practices that needed to be changed or acquired<sup>75</sup>—but, more importantly, to strategically craft messages to communicate information in such a way that persuades targeted audiences to recognize their own HIV risk

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<sup>75</sup> From this perspective, behaviour change aligned closely with the modernization/diffusion tradition in ICT4D, as discussed in Chapter Two, sharing the premise of deficiencies in knowledge, beliefs, or practices which needed to be revised, and the emphasis on transmission to passive audiences. Hence, this understanding of behaviour change can be especially problematic in development health communication contexts, generating ethnocentric and moralizing—and often ineffective—interventions, as we shall see below.



and to adopt appropriate preventive behaviours (Maibach et al. 1993, 15; Singhal 2003, 22). As a result, these practitioners turned to theories and models of health-related behaviour grounded in social psychology, developing ‘second generation’ interventions that were based on individual psychosocial and cognitive understandings of human behaviour, and involved educating individuals in practical risk-reduction skills through processes of instruction, modeling, practice, and feedback (Airhihenbuwa and Obregon 2000; McKee et al. 2004, 41; UNAIDS 1999, 5-6). Some of the behavioural theories embraced by mainstream health communication scholars and practitioners in the West that have been the most influential in the design, development, and implementation of HIV prevention interventions include the Health Belief Model (Becker 1974), the Theory of Reasoned Action (Fishbein and Ajzen 1975), Stages-of-Change Theory/Transtheoretical Model (Prochaska et al. 1994), Social Cognitive Theory (Bandura 1986), Diffusion of Innovations (Rogers 1962), and the AIDS Risk Reduction Model (Cantania et al. 1990).<sup>76</sup> See Appendix A for descriptions of each of these theories as they relate to HIV prevention.

Although these prevailing socio-psychological models of behaviour differ in their precise terminology, and in their conceptions of how various factors combine to predict health behaviour change, “most of these theories suggest that the most proximal influences on health behavior are attitudinal, social influence, self-efficacy and intention/stage of change variables” (Noar 2008, 276). Moreover, they mostly offer explanations of health attitudes and behaviour at the individual level, and this has important implications for their potential effectiveness in HIV/AIDS communication, as I will discuss below. While the earliest theories focused on the individual *in isolation*, the attention has generally shifted over the past three decades, at least in theory, to models that encompass broader social factors and

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<sup>76</sup> This summary is by no means exhaustive—numerous other behaviour-related theories have informed health communication scholarship and practice in various historical and social contexts. I only discuss here those theories that have been most prominent in campaigns and programs focused specifically on HIV or development contexts.

that consider multiple levels of influence—individual, institutional, community, and policy (Glanz et al. 2002, 7-9). Yet, individual-oriented models persist in theory and practice, and even the more social models still focus on the individual as the unit of analysis and rarely target broader environmental or structural levels of change (Fukuda and Ebina 2011, 174; Lupton 1994; McKee et al. 2004, 41; Melkote et al. 2000; Singhal 2003, 22).

### *3.1.2 From Theory to Execution: Behaviour Change Communication*

The application of these dominant theories of behaviour change in health communication practice has engendered a number of prevalent communication interventions, often collectively referred to as Behaviour Change Communication (BCC).<sup>77</sup> BCC strategies have been particularly influential in communication initiatives for HIV prevention, especially given the imperative of reducing risky sexual behaviour so as to prevent transmission.

Although BCC has been defined in different ways by different academics, institutions, and practitioners—reflecting the evolving nature of the field—we can draw on the general definition offered by the Academy for Educational Development's (AED) Center for Global Health Communication and Marketing:

Behavior change communication (BCC) is the strategic use of communication to promote positive health outcomes, based on proven theories and models of behavior change. BCC employs a systematic process beginning with formative research and behavior analysis, followed by communication planning, implementation, and monitoring and evaluation. Audiences are carefully segmented, messages and materials are pre-tested, and both mass media and interpersonal channels are used to achieve defined behavioral objectives. (AED)

This definition speaks to the highly planned and strategic nature of BCC, which attempts to

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<sup>77</sup> The term Information, Education, and Communication (IEC) has also been frequently used to describe this strategic use of communication to inform and educate the public about health risks and promote positive health behaviours. BCC has in many cases been adopted as the preferred term, to place more emphasis on the 'bottom line' of changing behaviour, despite the paternalistic and sometimes ethnocentric connotations associated with the term 'behaviour change' (Green 2003, 56). Some organizations have defined BCC as a more interactive process that encompasses both IEC (a more transmission-based approach) and the involvement of the targeted community not only to provide information but also to develop a supportive environment for behaviour change (for example, McKee et al. 2008; UNAIDS 2011). However, such involvement has often been restricted to very limited roles (i.e., providing feedback during formative research and pre-testing of messages) in mainstream BCC approaches (Ford et al. 2003, 602).

systematically measure outcomes of communication interventions, and hence is often seen as ‘scientific’ (Ford et al. 2003, 601). Whether through mass-mediated or interpersonal channels of communication,<sup>78</sup> mainstream BCC approaches used both in the West and in Africa have been primarily based on unidirectional linear transmission models of communication, generally following the “Sender-Message-Channel-Receiver” approach (Berlo 1960) to communicate persuasive health behaviour messages in a top-down fashion (Ford et al. 2003, 601-2; Lupton 1994). The unidirectional nature of this communication, with emphasis on achieving the effective transmission of messages whose content is determined by the sender, has engendered significant criticism, as I will describe below.

With respect to HIV and AIDS, BCC campaigns have mostly focused on changing sexual behaviour, with a particular emphasis on promoting the use of condoms as the best way to avoid HIV infection.<sup>79</sup> This has resulted in a proliferation of public service announcements (PSAs), billboards, and other public information campaigns promoting condoms and safer sex practices, as well as mass distribution of cheap condoms to clinics, shops, and bars<sup>80</sup> (Epstein 2008, 145). A select few BCC campaigns have also promoted partner reduction and fidelity, such as the frequently cited “Zero Grazing”<sup>81</sup> (having only one partner and reducing casual sexual encounters) approach promoted in Uganda in the late 1980s and early 1990s with considerable success (Epstein 176-7; Green 2003, 11-12;

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<sup>78</sup> Many health communication scholars and practitioners have argued that a false dichotomy exists between interpersonal and mass communication, advocating rather for a combined approach incorporating multiple communication channels simultaneously (Freimuth 1992, 108; Maibach 1993, 26; UNAIDS 1999).

<sup>79</sup> Although harm reduction strategies (policies or programs aimed at reducing the harmful consequences of recreational drug use, see Friedman et al. 2007) have also factored into BCC interventions, these have been far less prominent than those focused on sexual behaviour, particularly in African contexts (Susser 2009, 47).

<sup>80</sup> However, there has been significant gender disparity in condom promotion and distribution, with the vast majority of emphasis being placed on male condoms, despite female condoms being at least as efficacious, feasible, and cost-effective, with the additional benefit of being controlled by the woman, who is often the most vulnerable (Susser 2009, 29-31).

<sup>81</sup> Although many health communication practitioners and AIDS policy-makers have balked at the recommendation of introducing interventions promoting ‘faithfulness’ or ‘fidelity,’ arguing that this amounts to moralizing—a valid concern, particularly in the context of Western-led interventions in African settings, as I will discuss below—it should be noted that Uganda’s Zero Grazing campaign was endogenously developed, with sensitivity to specific cultural contexts. For example, Epstein argues, “The Zero Grazing message recognized the vital importance of partner reduction but also the difficulty of promoting lifelong monogamy in a culture in which polygamy and informal long-term concurrent relationships were common... Zero Grazing recognized that polygamy, both formal and informal, was normative and legitimate” (2008, 196-7).

Thornton 2008, 83-85).

One BCC message that encompasses both of these HIV prevention strategies (condom use and partner reduction) and is worth noting in particular—it has perhaps the most widespread adoption rate on the African continent—is the “ABC” approach, which encourages people to abstain from sex or delay their sexual debut, be faithful to only one partner, and use condoms every time they have sex. The ABC message<sup>82</sup> has been heavily promoted by international development agencies involved in AIDS intervention, particularly US President George W. Bush’s PEPFAR program, which shifted the model to place a particular emphasis on the ‘A’ (Susser 2009, 47-48; Thornton 2008, 83-84). Although the majority of PEPFAR funding was mandated for HIV treatment and care programs,<sup>83</sup> for its prevention spending PEPFAR developed a focus on abstinence-only education, allocating one third of its total prevention spending for programs that promote abstinence until marriage—despite a lack of evidence for the effectiveness of this approach—while only deeming condom education appropriate for those practicing ‘high-risk’ sexual behaviours<sup>84</sup> (Coates et al. 2008, 673; Epstein 2008, 187-189; Mbugua 2009, 172; Thornton 2008, 85-86). This focus, along with related PEPFAR legislation influenced by Christian conservatives in the US, had the effect of cutting off funding for any programs related to reproductive choice or abortion, and stifling interventions related to condoms, voluntary counselling and testing

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<sup>82</sup> Susser contrasts this with a perhaps more needed CNN approach: condoms, needles, negotiating skills (2009, 52).

Similarly, African HIV activists have recently called for the replacement of the moral and sexual-focused ABC approach with a new, more holistic prevention strategy called SAVE: Safer practices, Access to treatment, Voluntary counselling and testing, and Empowerment (Nzwili 2012).

<sup>83</sup> This includes 55% of overall funding being directed to the purchase of patented US pharmaceuticals, as opposed to the drastically cheaper generic medicines (Susser 2009, 47).

<sup>84</sup> Susser refers to the Bush administration’s abstinence policies for PEPFAR funding as a sort of “imperial morality,” in which this powerful state is using the largest proportion of money available for HIV and AIDS programs worldwide as an instrument to influence international policies around sexuality, sex education, women’s reproductive health, and gender-based violence. She notes the profound impact that these imperial moralities have had on AIDS prevention possibilities worldwide, ultimately violating human rights by failing to provide comprehensive sex education, counselling, reproductive choice, and harm reduction (Susser 2009, 45-49). Although this moralistic allocation for abstinence-only prevention was removed from PEPFAR legislation in 2008, these funding priorities from this extremely important donor had already severely restricted prevention possibilities in recipient countries in Africa and elsewhere, with repercussions stretching far beyond the first five years of PEPFAR (Susser 2009).

(VCT), harm reduction, comprehensive sex education, or work with MSM or sex workers<sup>85</sup> (Susser 2009, 48-49; Thornton 2008, 83). The ABC message for HIV prevention has been the subject of widespread critique for its oversimplified and often inappropriate nature, falling “severely short of describing the global effort needed to reduce HIV transmission... The ABCs infantilize prevention, oversimplifying what should be an ongoing, strategic approach to reducing incidence” (Collins et al. 2008, S5). While many ABC initiatives have emphasized only one element of this prevention triad, it is clear that even a comprehensive intervention, combining all three elements in unison, will be inadequate for achieving and sustaining reductions in HIV transmission (Coates et al. 2008, 673; Collins et al. 2008; Fuller 2008, 21; Thornton 2008, 87).

Health communicators are learning, then, that BCC messages for HIV prevention need to target behaviour change on multiple levels simultaneously. This is reflected in the design of increasingly complex and multidimensional BCC approaches, moving from simplistic condom billboards to multi-faceted campaigns across multiple communication channels, promoting a range of preventive behaviours. Although BCC interventions have been realized differently in different contexts (depending upon the behavioural theory applied implicitly or explicitly, the identified behaviour change goals, and the communication channels available), two prominent BCC models that have been particularly influential in AIDS and development contexts are social marketing and entertainment-education.

Since the 1970s, social marketing has been one of the most dominant BCC approaches, particularly in developing nations. It is based on the notion of applying the

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<sup>85</sup> This criticism is not meant to discredit the important contributions PEPFAR has made to HIV/AIDS work in Africa and elsewhere—benefits I have witnessed first-hand in my work on a PEPFAR-funded assignment in South Africa in 2009—but rather to highlight the importance of understanding the implications of this political legacy so that such limiting moralistic restrictions might be avoided in the future.

standard techniques of commercial marketing to health issues in order to promote particular behaviours, such as breast feeding, immunization programs, and family planning (Fukuda and Ebina 2011, 176; Waisbord 2001). Social marketing has been applied extensively in AIDS interventions, particularly for condom promotion, where it draws on the four Ps of the “marketing mix”—product, price, place, and promotion—to make condom use attractive, available, and affordable (Airhihenbuwa and Obregon 2000, 8; Freimuth 1992, 103-4; UNAIDS 1999; Waisbord 2001). Social marketing has offered vital lessons to the field of health communication, including the value of audience segmentation, formative research, and pre-testing of health messages (Lombardo and Léger 2007; Snyder 2007, S34). Yet, it has been widely criticized for its top-down approach<sup>86</sup> and questionable ethics, including the use of manipulation and fear, and the possible conflicting interests or motives of sponsors (Airhihenbuwa and Obregon 2000, 8; Freimuth 1992, 103-4; Waisbord 2001). Moreover, in ‘selling’ health behaviours like any other product, health becomes a commodity that consumers are persuaded to acquire at some cost to themselves, rather than a fundamental human right (Lupton 1994, 56). While social marketing may work well for some BCC campaigns with simple messages such as “use a condom,” and can integrate well with condom companies’ own advertising priorities, it is generally less adept at communicating more complex and multi-dimensional prevention messages, such as are needed to reduce HIV transmission.

Some health communication scholars and practitioners have turned to entertainment-education—sometimes called ‘edutainment’—as perhaps a better vehicle for more holistic BCC strategies. The entertainment-education approach aims to maximize both the reach and the effectiveness of health messages: it uses entertaining formats, especially in mass media,

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<sup>86</sup> Based on theories of individual behaviour change, this approach has many similarities to the diffusion of innovations model in particular, and conceives communication as a process of top-down transmission and persuasion (Airhihenbuwa and Obregon 2000, 8; Waisbord 2001).

to increase knowledge of an issue, foster favourable attitudes, and ultimately change behaviour through the purposeful design and implementation of media messages that both entertain and educate (Singhal and Rogers 1999; Singhal et al. 2004). This strategy is based on an appreciation of the potentially powerful and persuasive reach of media, and the notion that media products are so pervasive that they can, and should, be harnessed for positive social change. Entertainment-education draws on the dominant behaviour change theories,<sup>87</sup> and generally involves in-depth formative research to systematically develop educational messages appropriate to audience knowledge, opinions, and needs (Singhal et al. 2004; Tufte 2008; Waisbord 2001). The use of melodramatic and captivating narrative formats encourages greater emotional engagement with the fictive characters who function as ‘good’ and ‘bad’ behavioural role models (Tufte 2008, 336; Waisbord 2001). This approach has been implemented for a wide range of health and social issues worldwide, realized across a diverse range of media and narrative forms—including theatre, songs and music videos, comics, radio soap operas and television dramas—but edutainment applications have been particularly common in AIDS education and awareness programs on the African continent<sup>88</sup> (Fuller 2008, 20; Singhal et al. 2004; Tufte 2008, 337).

Examinations of the outcomes of AIDS-related edutainment programs in Africa have produced mixed findings, generating debates about the potential effectiveness of this health

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<sup>87</sup> It draws particularly on Bandura’s Social Cognitive Theory (SCT) and his concepts of modeling and self-efficacy, which are described in Appendix A.

<sup>88</sup> One particularly notable example described by Tufte (2008) is “Soul City,” the longest-running multimedia AIDS intervention in South Africa. Initiated in 1994, Soul City is a multimedia edutainment vehicle that combines television and radio drama, print materials, and other communication channels in education systems to tell the story of a collection of characters living in the fictional township of Soul City and the many impacts of HIV and AIDS on their lives. The scope of this program is immense: by 1999, Soul City had reached 16.2 million South Africans, including 79% of 16-24 year olds, 71% of 25-35 year olds, and 49% of people aged 46 and above (2008, 328). Given its wide popularity amongst young people in particular, Soul City has become a prominent platform from which to provide accurate HIV education and tackle the complex web of socio-cultural issues related to AIDS. In recent years, the goals of Soul City’s HIV/AIDS programming have stretched beyond individual behaviour change to include broader social mobilization and advocacy—alternatives to classic health communication strategies I will discuss below. Soul City has been lauded as widely effective, with behavioural and social change reported amongst audiences. This success has been credited to its multi-level approach as a coordinated communication campaign across many media formats, grounded in formative and summative research and local cultural contexts, including extensive reliance on local writers and creative teams (Goldstein et al. 2008; Singhal et al. 2004; Tufte 2008).

communication approach, particularly over longer timeframes. Some more optimistic studies report significant success (for example, Singhal et al. 2004, Vaughn et al. 2000). Other studies are more skeptical, suggesting that while edutainment is perhaps effective at awareness-raising and encouraging behaviour change in people pre-disposed to do so, it may have little long-term impact on others (Waisbord 2001; Yoder et al. 1996). In general, it appears that the effects of AIDS edutainment interventions are greatest when integrated as part of coordinated multimedia communication campaigns, especially when combined with interpersonal communication, and when they extend the focus of ‘educational’ messages beyond the realm of individual behaviour to address the broader social contexts of the epidemic (Singhal et al. 2004, 146; Tufte 2008). Indeed, attentiveness to these broader contexts is a critical element of success in all BCC approaches, and its absence in mainstream behaviour change interventions has considerably constrained the possibilities for AIDS prevention.

### **3.2 Limitations and Lessons: Critiquing the Dominant Models**

Despite their prominence, these paradigmatic, Western-based behaviour change theories and their corresponding communication-based models for HIV and AIDS intervention have garnered significant criticism for a range of limitations, which are particularly manifest in African cultural contexts. In the early years of the HIV epidemic, public health agencies, NGOs and other interventionists, responding largely in ‘crisis-mode,’ adapted bio-behavioural theories from previous interventions targeting other health issues such as vaccinations and nutrition. As a result, AIDS has been treated primarily as a health issue, with emphasis placed on designing and delivering health education messages and providing medical treatment (Ford et al. 2003, 600). However, as discussed in Chapter One, AIDS is more than just a health problem. It is a complex development challenge, impacting



different communities in different ways, and its unique nature as a multi-faceted epidemic with socio-cultural, economic, and political dimensions means that AIDS affects and is affected by all sectors of social life (Ford et al. 2003; Lie 2008; Tufte 2008, 333). Thus, the application of BCC models adapted from other health and development programs was inadequate from the start, failing to understand HIV as a particularly complex cultural, socio-economic and political issue. What works for immunization programs cannot readily be employed to communicate about a virus that is intertwined with personal, habitual, and often delicate or taboo topics such as sexuality and illegal drug use—necessarily involving sexual relationships, emotions, gender relations, and cultural norms, values, and practices—and that is encircled by negative connotations or social barriers of stigma and discrimination<sup>89</sup> (Ford et al. 2003, 604; Lie 2008, 280; Maibach et al. 1993, 17). As a result, HIV/AIDS communication interventions have been largely ineffective, isolated, and/or reductionist in approach.

Although different theories have provoked different critiques, in general the primary shortcomings of these mainstream socio-psychological behavioural models and communication approaches are, as described in the following four sub-sections: (1) their focus on ‘rational’ individuals; (2) their failure to account for socio-structural factors influencing behaviour; (3) their lack of perspectives on gender and sexual politics; and (4) their often ethnocentric adoption with inadequate consideration of the specific cultural contexts in developing nations.

### *3.2.1 Focus on Rational Individuals*

HIV/AIDS communication in the BCC tradition has been primarily guided by the paradigmatic individual-oriented behaviour change theories discussed above, and hence has

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<sup>89</sup> Moreover, strategies to stimulate one-time actions such as immunizations are not necessarily adequate to inspire lifelong changes in a particular complex behaviour, such as maintaining consistent condom use (Tufte 2008, 334).

tended to emphasize the importance of reason, knowledge, and personal intentions, focusing on rational choices and individual transformations without due consideration of the complex reality of the HIV epidemic (Airhihenbuwa and Obregon 2000, 8; Coates et al. 2008, 676). A primary concern with this cognitive, individualistic focus in HIV/AIDS communication is the often fallacious assumption of rational decision-making, assuming people have both the motivation and the freedom to adopt protective practices (Freimuth 1992, 109; McKee 2004, 43; Melkote et al. 2000; Singhal 2003, 22). Yet decisions pertaining to health—sexual behaviour in particular—are often explicitly irrational, and thus HIV risk cannot realistically be addressed solely from such a logical perspective. Indeed, sexual behaviour often has more to do with love, desire, emotion, physiological needs, power relations, social pressure, and external forces than with rational, volitional thinking<sup>90</sup> (Airhihenbuwa and Obregon 2000, 7; Melkote et al. 2000, 19; Michal-Johnson and Bowen 1992, 153; Tufte 2008, 334). Likewise, given the prevalent perception of ‘immoral’ or ‘irresponsible’ behaviour in acquiring HIV—connotations of exceptional promiscuity or illegal drug use persist, despite most HIV transmission being rather normative—the epidemic remains shrouded in intense stigma (Epstein 2008, xvii). Although poverty, gender, age, religion, and government policy can act as moderating variables, stigma continues to be an important determinant in health care-seeking behaviour in, for example, sub-Saharan Africa (Mbonu et al. 2009). Many people are unwilling to learn or disclose their seropositive status, seek treatment, or even insist upon preventive behaviours such as condom use, because of the stigma associated with HIV and AIDS. Thus, the assumption that individuals act ‘rationally’ when making preventive health decisions neglects the significant impact of affective and social influences on health behaviour.

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<sup>90</sup> Although this is perhaps most cogently illustrated vis-à-vis sex and HIV risk, the assumption that people not only have the desire but also the capacity to change their behaviour applies to all areas of health communication, from dietary behaviours to substance abuse (Snyder 2007, S36).

Moreover, the emphasis on rational individuals renders health communication both apolitical and inappropriate in certain cultural milieus. At the heart of most BCC approaches lies an individualistic understanding of health, which conceptualizes individual behaviour and ‘lifestyle’ choices as primarily responsible for health problems, and hence positions individuals—not communities or states—as responsible for enacting change to ensure a healthier population (Waisbord 2001, 11-12). Yet, as Coates et al. remind us, HIV transmission is a social event, in which “many factors other than an individual’s perceived threat, knowledge, self-efficacy, behavioural intentions, and perceived social norms affect whether or not sexual intercourse will potentially involve transmission risk” (2008, 676). This necessitates a more holistic social analysis and social approach to intervention—positioning behaviour in a wider social context—which has been largely absent in mainstream BCC approaches.

Even models that take into account the influence of family and community still see the individual as the unit of rational decision-making, and therefore fail to adequately recognize the influence of broader contextual and environment factors that imperil health. This conceptualization of health has been heavily criticized: not only does it sometimes result in ‘blaming the victim,’ but more critically it obviates assessment of social conditions that beget unhealthy behaviour, which has the overall effect of depoliticizing the question of health behaviour (Lupton 1994, 57; Waisbord 2001). By ignoring social contextual factors and focusing on personal change at the expense of community actions and responsibility, these bio-behavioural theories of individual change neglect the need for systems-level change (Salmon and Kroger 1992, 131). This is especially problematic in African countries where the family and the community are central both to decision-making processes and to the conceptualization of health and well-being (Airhihenbuwa and Obregon 2000, 9).

### 3.2.2 *Structural Factors and Constraints*

The primary issue with this focus on the ‘rational’ individual in isolation, then, is that it largely ignores the broader social and structural factors<sup>91</sup> that shape individual behaviour, and in the context of HIV, enable or constrain individuals to take action to reduce risk and mitigate social vulnerability. Consideration of these socio-structural determinants is absolutely paramount in addressing HIV, yet the mainstream bio-behavioural approach to disease—which posits that disease can be halted by targeting individuals or risk groups—critically neglects these factors. Singhal (2003) likens this to focusing solely on the tree, while neglecting the broader socio-cultural forest of which it is a part. Without an understanding of the complexities and interactions of the forest in its entirety, any intervention targeting the tree will be critically limited. Likewise, HIV transmission does not occur in a vacuum, and the epidemic is not merely a biological phenomenon—it has socio-structural determinants as well, exacerbated by globalization, racism, sexism, and other stigmatizing processes, as well as the legacies of colonialism, war, political instability, poverty, gender inequality, and exploitation (Dean and Fenton 2010; Friedland 2006, S6; Green and Ruark 2011, 177-185; Gupta et al. 2008; Klein et al. 2002; Susser 2009). The dominant approaches to HIV/AIDS communication have given inadequate attention these complex realities.

BCC strategies have too often assumed that “all individuals are capable of controlling their context. However, whether or not an individual can get an HIV test, use condoms, be monogamous, and/or use clean needles are all affected by cultural, economic, social, and political factors over which the individual may exercise little control” (Singhal 2003, 22).

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<sup>91</sup> The social and structural factors affecting HIV and AIDS include the physical, social, cultural, organizational, economic, legal, and policy aspects of one’s environment that restrict or facilitate the capacity of individuals to access information and services related to HIV—from VCT to ART medication—and to take preventive measures to mitigate vulnerability to infection (Dean and Fenton 2010, 1; Gupta et al. 2008, 765; McKee et al 2008, 268-273; Melkote et al. 2000).

The most vulnerable and marginalized populations are often unable to achieve such autonomous self-determination, and instead find their choices limited by their social environment. Moreover, these dominant models have often wrongly assumed a ‘level playing field,’ although disparities in social and economic power mean that some individuals are more vulnerable than others (Singhal 2003, 22). For example, given the bearing of race, gender, and socioeconomic status on HIV-related behaviours, we know that not everyone is in an equal position to make decisions about condom use, either because condoms are unaffordable for people living in extreme poverty, or because unequal gender relations render this decision more likely to be made by the man.<sup>92</sup> Indeed, African women (and poor women of colour globally) experience the greatest vulnerability in this respect (Fuller 2008; Melkote et al. 2000; Susser 2009). In this manner, the many socio-political and economic conditions that impact behaviour and shape the health of communities often create further vulnerabilities for people who are already marginalized. Here, also, stigma and discrimination can compound this marginalization (Mbonu et al. 2009). Even if individuals have the motivation and desire to change their behaviour, not everyone has the capacity to do so because of these socio-structural constraints.

The nature of these constraints varies dramatically from community to community, underscoring the critical importance of developing context-specific approaches for each new intervention—in African countries and elsewhere—rather than attempting to imitate or transplant generic ‘best practices’ or standardized models. When we understand that an individual’s behaviour is shaped by diverse socio-structural factors, we recognize the need to

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<sup>92</sup> Condom promotion in this context is not only inadequate, but often detrimental, in that it obscures the genuine reasons for risky sexual behaviour, diminishing recognition of the need to address these underlying socio-structural constraints on behaviour (Tufté 2008, 334).

tailor interventions.<sup>93</sup> Thus, we must consider in each context the impacts of local health and education systems, legal and criminal justice processes, migration, war and conflict, government service provision, food security, employment opportunities, housing, postcolonial development, poverty, racism, sexism, gender inequality, social exclusion, stigma and discrimination, spirituality, cultural factors, and aspects of the natural environment on HIV and AIDS-related behaviour (Abdool Karim 2005; Dean and Fenton 2010; Klein et al. 2002; McKee et al 2008; White et al. 2009). These are clearly broad-based social and systemic issues, not individual problems; and thus we can see that the framework of the entire ‘behaviour change’ mentality is rendered grossly inadequate.

### 3.2.3 *Gender, Sexuality, and HIV Vulnerability*

One socio-structural factor worth examining in particular is gender and sexual inequality, and the ways in which it constrains behaviour and contributes to HIV risk. As elaborated in Chapter One, women and girls are disproportionately affected by the epidemic, especially in sub-Saharan Africa, where young women aged 15-24 are up to eight times more likely to be HIV positive than men (Kalipeni et al. 2009; Susser 2009; UNAIDS 2010, 10). Yet throughout the history of the epidemic, coordinated and sustained international interest in gender issues relating to HIV has been sporadic, and hence inadequate attention has been paid to the feminization of the epidemic, the specific and complex vulnerabilities for women, and the ways in which gender inequality can be addressed in AIDS intervention<sup>94</sup> (Susser 2009). Fuller (2008) has offered a strong gender critique of mainstream communication responses to the epidemic, arguing that many behaviour change approaches have failed to

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<sup>93</sup> As Lupton has argued, this critical perspective engenders a necessarily political approach, “questioning the values of biomedicine and focusing on the identification of the political, economic, and historical factors that shape a culture’s responses to and concepts of health, disease, and treatment issues” (1994, 58).

<sup>94</sup> Susser notes that there has often been emphasis placed on preventing maternal transmission, without consideration of the vulnerabilities to infection of women themselves (2009, 41-44). Although more recently women have become more visible in AIDS discourses, and literature on gender perspectives on HIV has increased (see Boesten and Poku 2009 for an excellent contribution in this area), it remains to be seen whether mainstream interventions will adequately address gender inequality as a central component of prevention and treatment efforts.

take account of the African sociocultural landscape and the complex dynamics of gender in this context—disparities that are critical to understand and appreciate before suitable responses can be mounted (2008, 21).

A gendered analysis reveals that African women face a unique combination of vulnerabilities that position them in a place of exceptional susceptibility vis-à-vis HIV and AIDS. In addition to their greater physiological vulnerability to infection, deeply entrenched gender inequality means that African women face additional socio-cultural, educational, economic, legal and political vulnerabilities—the structural factors discussed above map onto gender in unequal and complex ways (Abdool Karim 2005; Boesten and Poku 2009; Fuller 2008; Gupta and Weiss 2009; Kalipeni et al. 2009; Susser 2009). From genital mutilation and gender-based violence,<sup>95</sup> to a property rights dispossession and economic dependence on men, to constrained access to primary education and other social services, these women are subject to gender-based inequality that is exacerbated by racism and poverty, has been compounded by globalization, and directly contributes to HIV risk (Fuller 2008; Gupta and Weiss 2009; Mbilizi and Semu 2009; Susser 2009; UNAIDS 2010, 10). Poor women bear most of the burden of caring for the sick and those orphaned by AIDS, and they continue to experience income inequality and reduced access to both HIV prevention and treatment (Fuller 2008; Nyirenda et al. 2006; Susser 2009, 4, 26). Young girls are particularly vulnerable,<sup>96</sup> being less educated, less empowered socio-economically, and more prone to coercion, sexual violence, and dependence on older men (Ghanotakis et al. 2009, 359; Kalipeni et al 2009).

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<sup>95</sup> Gender-based violence (GBV) is extraordinarily prevalent in South Africa in particular, which has the highest figures of GBV for a country not at war, and one of the highest rates of reported rape in the world (Epstein 2008, 73-85; Ghanotakis et al. 2009; Jewkes et al. 2009; Moffett 2006). At least one in three South African women will be raped in her lifetime, and quite commonly this violence is perpetrated by a partner or someone known to the woman (Dunkle et al. 2004a; Moffett 2006). Group rape and child sexual assault are not uncommon (Dunkle et al. 2004a; Wood 2005). This “gender civil war” (Moffett 2006, 129) gives rise to significant HIV risk for these women (Dunkle et al. 2004a), and hence poses a considerable challenge to the design of HIV communication interventions. Thus it is essential that the “dual epidemics” (Ghanotakis et al. 2009, 359) of HIV and GBV be tackled in unison, integrating gendered perspectives into all aspects of AIDS intervention.

<sup>96</sup> In South Africa, for example, these girls contract HIV as young teens, at least five to ten years earlier than men (Abdool Karim 2005, 245; Harrison 2005, 265).

The marginalization and economic vulnerability of these women and girls—facing poverty and a lack of economic alternatives—often leads to sex work or transactional sex,<sup>97</sup> and when they are unable to negotiate condom use in these encounters and relationships, they find themselves at great risk for HIV (Airhihenbuwa et al. 2000, 107-8; Boesten and Poku 2009, 11; Dunkle et al. 2004b; Epstein 2008, 73-79; Fuller 2008; Gupta and Weiss 2009;).

Although it is clear that power disparities between men and women exacerbate HIV—in the African context and elsewhere—most AIDS discourses and communication interventions simply fail to understand or address the intersection of power, sexuality, and culture (Mbilizi and Semu 2009). Communication strategies have often failed to tailor appropriately for the particular needs of men and women vis-à-vis HIV. For example, past BCC campaigns promoting condom use have inappropriately targeted women alone with these messages, a legacy of approaches based on family planning and population programs (Tufté 2008, 334). In reality, their husbands, boyfriends, and clients need to be encouraged as well, because these decisions are often made exclusively by the male partner<sup>98</sup> (Harrison 2005; Singhal 2003, 22; Susser 2009, 29).

The importance of gendered analysis in the design of HIV and AIDS communication is exemplified by the shortcomings of the ABC campaigns—a mainstay of HIV prevention programs on the African continent—and an examination of what they actually offer most women. In theory, the ABC paradigm offers a triad of prevention choices and thus presents women with more options than simply promoting one method in isolation, as is the case with

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<sup>97</sup> We can distinguish formal sex work from the type of transactional sexual relationships that are extremely common in southern Africa, which are characterized by expectations of gifts of cash or material goods (Dunkle et al. 2004b; Epstein 2008; 76-78; Luke and Kurz 2002). Unlike formal sex work, in which a price is set in a business-like transaction, transactional sexual relationships involve emotions and commitment, and the gifts are often less important than the social connections they represent. However, as these authors explain, these relationships—which are characterized by some degree of trust and love, but also often by concurrency with other sexual partnerships—may be associated with even greater HIV risk than more formal sex work.

<sup>98</sup> Although I am focusing here on the African context, similar limitations have long been recognized in the West (see, for example, Worth 1989).



much-criticized abstinence-only education programs. Yet despite billions of dollars in resources being invested in teaching the ABC model, it has been persistently rejected by sub-Saharan Africans (Mbugua 2009). This is because the ABC formula remains a technical solution that confuses the end goals of behaviour change with the strategies necessary to effect such change. As a result, in many instances ABC is completely inappropriate for the complex realities of women's lives, failing to account for the critical realities of gender inequality and its impacts on sexual decision-making (Boesten and Poku 2009, 14). Since the power and decision-making in sexual relationships often rest with the male partner, for socio-cultural, economic, or legal/political reasons, many women are unable to abstain from sex, rely on the fidelity of their partner, or insist on consistent and correct condom usage (Abdool Karim 2005; Fuller 2008; Harrison 2005; Imbembe 2009; Mbugua 2009; Susser 2009). Abstinence also becomes irrelevant in the context of marriage and reproduction. Being faithful to one's partner matters little if he is not faithful as well or if a woman is raped by another man, and the notion of fidelity is complicated by concurrent relationships that are rather normative in many African cultures.<sup>99</sup> Condoms may be opposed for a plethora of religious, cultural, or economic reasons, or because of personal beliefs fueled by ignorance, myth, or conspiracy theories<sup>100</sup> (Mbugua 2009). Sex workers either may not be able to

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<sup>99</sup> Epstein (2008) has argued that the prevalence of concurrent sexual partnerships in some African cultures—either in formal polygamy or more informal, yet still normative, arrangements—has been significant in the spread of HIV. She notes that, quite contrary to popular discursive constructions of African promiscuity and exotic sexual practices, these forms of long-term concurrency are actually characterized by a rather small number of sexual partners over one's life—perhaps fewer than is common in the patterns of serial monogamy that are common in the West—but the concurrent nature of these relationships confers significant HIV risk because it links people into broad sexual networks that facilitate the spread of the virus. Hence, she suggests that the ABC messages and especially the condom social marketing campaigns are problematic in many African contexts because they are often transplanted from contexts where sexual behaviour is governed by very different moral rules and norms (Epstein 2008, especially 141-152). However, as Mbugua (2009) describes, African polygamy can be termed “monogamous polygamy,” (i.e., faithfulness within the confines of a polygamous marriage) and contrasted against “polygamous monogamy” (i.e., serial monogamy with faithfulness to a single partner at a time, *ad infinitum*). While the former poses no HIV risk if all parties of the marriage are seronegative, the latter can indeed generate significant HIV risk if one partner in the series is seropositive. Thus, the ‘B’ approach to prevention is not only ambiguous, but also potentially misleading.

<sup>100</sup> For example, conspiracy theories include the notion that HIV is a Western invention to annihilate African populations, or that the real purpose of condom promotion is either to reduce population growth in Africa by preventing pregnancies or to generate profits for Western condom manufacturers (Mbugua 2009, 179).

persuade clients to wear a condom, or they may choose to have unprotected sex for a higher price. Moreover, Susser reminds us that the ‘C’ of the ABC model refers almost universally to male condoms: although an equally efficacious female condom has been available for nearly two decades, there has been huge disparity in the promotion and accessibility of female condoms<sup>101</sup> (2009, 29-31). Quite simply, this prevention recipe, while catchy, does not take into account the socio-structural conditions under which a woman is not in a position where she is empowered to negotiate A, B, or C. Hence, ABC will only work as part of a comprehensive response that also, crucially, attends to these gender-based imbalances, recognizing the feminization of poverty and integrating empowerment and advocacy for the rights of girls (Fuller 2008, 21). HIV and AIDS communication interventions that fail to consider women’s status in society and combat deep-rooted gender inequality will serve only to superficially treat the symptoms—while ignoring the underlying causes—of the vulnerabilities endured by these African women.

However, although they may be marginalized and face considerable risk, we must also remember that African women are “not merely puppets of globalization, cultural norms, or biological imperatives, but rather agents in their own livelihoods” (Kalipeni et al. 2009). Indeed, these women are not just passive victims subjected to various socio-structural constraints; they employ their agency in creative and diverse ways to cope with these vulnerabilities and mitigate their HIV risk, infection, or that of those around them. In my experience, it is the strength and resilience of these women that has been most inspiring in any hopeful pursuit of progress in abating the epidemic.

We must also recognize that ‘gender’ is not synonymous with ‘women’; it refers to

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<sup>101</sup> Evidence from Brazil suggests that the introduction of the female condom may substantially increase the number of protected sexual acts (Abdool Karim 2005, 251). Yet many HIV prevention programs continue to revolve around the cheap and widespread distribution of male condoms. An invisible microbicide that would have the capacity to kill the virus while still allowing pregnancy is another desirable, yet still elusive, option (Susser 2009, 32).

the socially constructed and culture-specific expectations of male and female roles, responsibilities, and behaviours, and the corresponding interactions and experiences of men and women (Boesten and Poku 2009; Gupta and Weiss 2009, 61). Although women experience exceptional susceptibility in the African context, the reality is that persistent gender inequalities contribute to *both* men's and women's vulnerability to HIV. Cultural norms and expectations of masculinity and femininity impact both men's and women's access to information and services, their likelihood to adopt preventive practices, and their ability to cope with the virus (Abdool Karim 2005; Colvin and Robins 2009; Gupta and Weiss 2009). For example, in many cultures hypersexuality, dominance, promiscuity, and risk-taking behaviour are linked with hegemonic ideologies of masculinity, and when such notions of masculinity are acted out, HIV risk ultimately increases for both women *and* men (Abdool Karim 2005, 253-4; Gupta and Weiss 2009, 63; Simpson 2008). Yet gender-specific vulnerabilities to HIV among men have rarely been considered in the African context (Green and Ruark 2011, 187; Harrison 2005, 265). The sexual politics of same-sex relationships, rendered invisible in mainstream discourses about AIDS and Africa, call for particular consideration here because of the impacts of criminalization, a persistent and imposing structural factor in many African nations (Lorway 2008; Mbilizi and Semu 2009; Phillips 2004). For example, in his discussion of the particular HIV vulnerabilities of young MSM in Namibia, Lorway (2008) has illustrated the considerable challenges inherent in promoting safe same-sex sexual practices in a political climate that sanctions homophobia. This is not only true in the African context, of course—Treichler (1999) has famously demonstrated the ways in which homophobia has permeated biomedical discourse to shape the possibilities for HIV research and intervention in negative ways—but these issues are especially pertinent and also especially invisible in an environment where same-sex sexual practices not only

remain stigmatized and discriminated against, but are also explicitly illegal.

In short, it is clear that any effective HIV intervention must first interrogate, understand, and attempt to address these many complex interrelationships between gender, sexuality, inequality, and HIV risk. Although such analysis may reveal that gender inequality puts African women at a significant disadvantage, we cannot divorce the reduction of HIV risk for women from the critical need to design AIDS communication interventions that attend to the complex and context-specific dynamics of *both* men's and women's particular gendered vulnerabilities.<sup>102</sup> Engaging in a gender-based response demands close attention to the cultural norms, values, and traditions that are inscribed on gender in each particular context, in order to alleviate gender inequality and strive to create more enabling environments.

### 3.2.4 *Culture and Ethnocentrism*

After years of unsuccessful HIV/AIDS communication programs in developing countries, rates of infection continued to rise. By the end of the twentieth century there was a growing consensus that these disappointing results demanded re-evaluation of the dominant behaviour change theories and approaches, in order to reassess their relevance for HIV and AIDS intervention in the parts of world most affected (Airhihenbuwa et al. 2000, 102; Lie 2008). Mainstream socio-psychological behavioural models and communication approaches have frequently been criticized for failing to incorporate culture as a central construct, and thus also failed to adequately theorize the limitations to application of these predominately Western-derived theories in other cultures (Airhihenbuwa and Obregon 2000; Freimuth 1992, 109; McKee et al. 2004, 42; Swanepoel and Hoeken 2008). Cultural values, norms, and

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<sup>102</sup> As I will discuss below, these communication interventions do not apply only to HIV prevention. As Nyirenda et al. (2006) have shown in Malawi, attention to gender issues is critical in the design and implementation of all HIV-related services, because gender inequality and the ways in which stigma is experienced differently by men and women affects access to HIV counseling, testing, and treatment, as well as adherence to ART.

practices are a primary determinant of individual behaviour, cutting across all other socio-structural factors and mediating decisions that can influence HIV risk in ways that may not be obvious to either the individual or the interventionist (Airhihenbuwa and Obregon 2000, 12; McKee et al. 2008, 272). Thus, we cannot reasonably expect ‘proven’ Western HIV prevention models to lend themselves to a straightforward transfer to non-Western cultural settings where there are different types of ‘common sense’ knowledge and different understandings of family, community, sex, and relationships. Yet, in the history of HIV and AIDS intervention in developing nations, too few practitioners have examined the cultural relativity of the paradigmatic models, instead simply replicating Western communication messages and strategies without adaptation or adjustment—for example, transplanting flashy, glamorous condom promotion billboards to rural villages and impoverished townships (Airhihenbuwa and Obregon 2000, 6; Airhihenbuwa and Webster 2004; Epstein 2008, 146).

These critiques are especially pertinent to an examination of the manner in which communication programs have addressed AIDS in sub-Saharan Africa. The design, implementation, and evaluation of HIV and AIDS communication in that region has often been ethnocentric in both in theory<sup>103</sup> and in practice, hindered either by an inadequate consideration of African cultural contexts or, more problematically, by a negative perception of that culture (Airhihenbuwa et al. 2000; Green 2003; McKee 2004, 42; Singhal 2003). Where ‘culture’ has been considered, it has been frequently positioned as a barrier, never a strength, that is invoked to explain or justify nonexistent, inadequate, or failed projects, blaming cultural beliefs or practices for inhibiting the desired behaviour change (Airhihenbuwa and Obregon 2000, 10; Singhal 2003, 24; Treichler 1999, 234). Designing

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<sup>103</sup> The literature on communication approaches to HIV prevention has revealed this Western bias and corresponding dearth of attention to the specific nuances and complexities of effectively introducing these interventions in African cultural contexts. For example, two of the most significant texts compiling communication perspectives on HIV and AIDS, edited by Edgar et al. (1992, 2008), feature scant mention of the continent most affected by the epidemic.

and implementing effective BCC, in this sense, is seen largely as a task of translating hegemonic Western biomedical ‘knowledge’ into forms that are somehow meaningful and useful in local contexts, in order to surmount the perceived ‘barrier’ of African traditions and cultural ‘beliefs’ (Treichler 1999, 223). Although perhaps unintentionally, in effect this metaphorical coupling of ‘culture’ and ‘barrier’ serves to perpetuate racist discursive constructions of the ‘backwardness’ of African cultures, to reinforce harmful ethnocentric assumptions that local African knowledge is somehow less ‘objective’ or ‘scientific’ than Western biomedicine, and to undervalue local communication practices such as the importance of oral communication as a genre in Africa<sup>104</sup> (Airhihenbuwa and Obregon 2000; 10-12; Lupton 1994, 58; Waisbord 2001). In short, African cultures are viewed as part of the problem, not part of the solution (Green and Ruark 2011, 57).

This negative view of African cultures is particularly problematic in discussions of African sexuality, and the long discursive history constructing African sexual practices as exotic. As Green and Ruark explain, “beginning in the 19<sup>th</sup> century, a number of explorers, adventurers, missionaries, and amateur anthropologists produced highly ethnocentric, sensational, moralizing accounts of native sexual behavior” (2011, 47). Contemporary AIDS discourses have reinvigorated these dangerously racist and pejorative constructions, perpetuating and reifying these colonial and postcolonial fantasies about an African sexuality that is dominated by supposedly ‘exotic’ practices—such as polygamy, widow inheritance, rampant promiscuity, rape and sexual coercion, ‘dry sex,’<sup>105</sup> widespread STIs, unsafe circumcision rituals and genital mutilation, and sex and marriage at extremely young ages, especially for girls—that purportedly contribute to the rapid spread of HIV on the continent

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<sup>104</sup> This follows the modernization conception of development, in which ‘modernity’ and ‘culture’ are perceived as two opposite ends of the spectrum of development, and where top-down paternalistic communication from (Western) ‘experts’ is required to overcome (African) ‘traditional’ beliefs (Airhihenbuwa and Obregon 2000, 11).

<sup>105</sup> ‘Dry sex’ refers to the practice of using plants or herbs to dry the vagina prior to sex (Treichler 1999, 207).

(Boesten and Poku 2009, 8; Green and Ruark 2011, 47; Simpson 2008, 119; Treichler 1999, 207). Such lurid depictions of African sexuality—as somehow opposed to a ‘white’ or ‘European’ sexuality<sup>106</sup>—have been perpetuated by mainstream medical, media, and academic AIDS discourses, locating blame for both the origin of the epidemic and its devastating effect on the continent on the purportedly exotic and promiscuous ‘African culture’ (Epstein 2008, 49-65; Patton 1999; Simpson 2008, 119; Treichler 1999). Many of these claims are sensationalized, distorted, and exaggerated,<sup>107</sup> and this focus on exotic ‘African’ cultural practices also ignores the immense cultural heterogeneity across the continent. Just as the entire continent has frequently been painted as an undifferentiated mass of suffering and disease, so too are the sexual and cultural practices of diverse peoples generalized across entire regions, and even across all of ‘Africa’ as a whole (Boesten and Poku 2009, 8; Patton 1999, 352; Treichler 1999, 206).

Focusing on the science—the supposed ‘Truth’ of AIDS—tends to obscure these distortions. However, as Crimp (1989), Treichler (1999) and others have argued, we must remember that AIDS exists not just in its manifestations as a biological syndrome, but also in and through practices that conceptualize, represent, and respond to it. Thus it is essential to interrogate these discursive constructions, and their material and political implications.

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<sup>106</sup> As Patton (1999) has argued, this discursively constructed African sexual Otherness—along with the notion of a (heterosexual) ‘African AIDS’ as entirely distinct from the AIDS experienced in the West—reveals less about African sexuality than the desire to preserve the sanctity and safety of our own privileged Western sexuality, allowing white Western heterosexuals to evade the fear that they too might be vulnerable to HIV. Moreover, such discursive emphasis on the condemnation of (African) promiscuity gives rise to the rather ludicrous notion that monogamy itself “affords some kind of intrinsic ‘moral’ defense against a retrovirus” (Watney 1989, 85).

<sup>107</sup> These claims in many cases bear little resemblance to the lived sexual experiences of Africans. Assumptions of a rampant African promiscuity have been proven baseless, since men and women in Africa report the same or fewer numbers of sexual partners than those in industrialized countries (Green and Ruark 2011; Boesten and Poku 2009, 8). It is not that these practices do not exist (many can be found in the West, too), but rather that they are often not as common as suggested, and these discourses of blame and ‘exotic’ sexuality sideline consideration of the rather normative sexual practices through which most HIV transmission occurs, such as in marriage and other long-term relationships. For example, the ‘baby rape’ hysteria in South Africa concerning the supposed myths that having sex with a virgin or an infant will ‘cure’ HIV has been intensely dramatized; these myths do exist in some communities, but not nearly to the extent suggested by the morally affronted Western news media (Epstein 2008 228-238; Jewkes et al. 2002; Posel 2005). As Patton (1999) suggests, these narratives are often less about evidence than about conforming to stereotypical Western discourse about African sexuality, familial relations, and ‘African’ AIDS.

Narratives of exoticism and blame serve not only to discursively construct Africans as the exotic Other, but also to cause real harm: by masking other important contextual factors, they compromise responses to the epidemic by distracting the focus and misguiding the interventions (Patton 1999; Treichler 1999). Therefore, this negative view of African cultures and sexual practices is not only ethnocentric, sensationalized, and derogatory, but it also gravely constrains the possibilities for HIV intervention on the continent. In addition to perpetuating communication initiatives that may be inappropriate for application in African cultural contexts, this focus almost exclusively on the negative aspects of African cultures that might contribute to HIV risk precludes recognition of the positive cultural strengths and practices that might mitigate the spread and impacts of the epidemic in Africa (Green and Ruark 2011, 47-64; Singhal 2003). African cultures can, and should, be seen as allies, positive enabling facets in any HIV/AIDS intervention. For example, prevention, care, and support programs should acknowledge and harness positive cultural attributes and strengths such as close familial bonds and community support networks, the cultural emphasis placed on sexual abstinence, the spiritual role of traditional healers, and the African philosophy of Ubuntu<sup>108</sup> (Epstein 2008; Green and Ruark 2011; Singhal 2003). Africans have actively and creatively responded to the epidemic since its start—not passively waited for apocalypse—and thus it is essential not only to make sense of HIV and AIDS in local cultural contexts and understandings, but also to seek out indigenous responses that have been successful and identify the cultural strengths that can be leveraged for positive change (Airhihenbuwa and Obregon 2000, 12; Treichler 1999, 206). Engaging in such culturally sensitive approaches that are context-specific and incorporate culture as a central organizing principle may not be as easy as transplanting ‘proven’ models and interventions, but it will likely prove more

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<sup>108</sup> Ubuntu is an African ethical philosophy of shared humanity and compassion, described in the Zulu saying, “A person is a person through other people” (Epstein 2008, 217).



effective and sustainable in the long run.

### **3.3 Beyond Behaviour Change: Alternative Approaches for Health Communication Interventions in AIDS**

As health communication scholars and practitioners have increasingly recognized the inadequacies of the dominant, socio-psychological, individual-oriented BCC models, acknowledging their failures and shortcomings both in theory and in practice, they have proposed alternative models and theoretical frameworks for designing HIV/AIDS communication interventions. These alternatives are not, however, new. As early as the end of the 1990s, UNAIDS (along with many others) recognized the need for alternatives, proposing a *new* “Communications Framework for HIV/AIDS.”<sup>109</sup> Although we have begun to see a paradigm shift toward more comprehensive context- and dialogue-based approaches that contemplate broader socio-cultural, political, and economic factors impacting behaviour—indeed, perhaps more so with AIDS than with other diseases, given the growing recognition of its complexity and several decades of often inadequate interventions—BCC language still prevails in many mainstream AIDS discourses, and intervention programming is still often at least implicitly informed by theories of individual behaviour (Ford et al. 2003; Lie 2008, 286-8; McKee et al. 2008; Obregon 2003; Tufte 2008, 333-334). More than a decade later, those UNAIDS recommendations remain very pertinent, articulating persistent core challenges in HIV/AIDS communication (Tufte 2008, 334). It is essential, therefore, that we examine the alternative responses that have been articulated, assess their potential, and

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<sup>109</sup> Between 1997 and 1999, UNAIDS led a series of workshops around the world (in collaboration with the Pennsylvania State University) in which leading health communication researchers and practitioners evaluated the effectiveness of theories guiding global HIV/AIDS communication (Airhihenbuwa et al. 2000; UNAIDS/Penn State 1999). The resulting publication identified the critical shortcomings of the dominant theories and models along the lines I have discussed above—the conclusion being that individual-oriented behaviour change theories provided an insufficient theoretical foundation on which to develop AIDS intervention—and proposed a new “Communications Framework for HIV/AIDS” that would look beyond individual behaviour to address the social environmental context (UNAIDS/Penn State 1999). This framework identified five interrelated “domains of context” that factored into HIV preventive behaviour: government policy, socioeconomic status, culture, gender relations, and spirituality. It suggested that these critical factors in the physical and social environment could be considered as a flexible framework to guide the development of HIV/AIDS communication interventions.

reaffirm their capacity to enhance health communication.

Many of the alternatives are implicitly suggested by the critiques I have presented above. In those critiques, new or modified ways of thinking about the purpose and design of HIV/AIDS communication were proposed, based on a central belief in the need to treat the broader socio-structural, demographic, and cultural factors not just as determinants influencing individual behaviour, but also explicitly as fundamental direct targets of change. If the dominant models articulated above have been criticized for targeting ‘rational individuals’ in a socio-structural, gender and cultural vacuum, it logically follows that proposed alternatives must be based on a central consideration of exactly these enabling and constraining factors. Specifically, we can identify four broad themes or categories of alternative health communication approaches or analytical frameworks relevant to addressing HIV and AIDS in development contexts: socio-structural, environmental, and cultural approaches; a human rights-based framework; advocacy communication; and participatory and empowerment approaches.

### *3.3.1 Socio-structural, Environmental, and Cultural Approaches*

Given the modest impact of individual and behavioural interventions on HIV risk, researchers and practitioners have advocated the development of social epidemiological analytical frameworks that extend analysis beyond individual cognitive and behavioural factors and incorporate consideration of the complex socio-political dynamics and environmental forces influencing behaviour related to HIV risk (Dean and Fenton 2010; Klein et al. 2002; Kreiger 2011; Melkote et al. 2000; White et al. 2009). For example, the “Risk Environment” Framework (Rhodes 2002), the Social Ecological Model (Larios et al. 2009; UNAIDS 1999, 11), and theories such as the Social Production of Disease, the Political Economy of Health, and the health and human rights approach (which I will discuss

separately below) (Kreiger 2001, 2011) have all addressed, to various extents, the fundamental underlying causes of social inequality in health, offering explanations of the powerful social, institutional, political, and economic contexts shaping individual behaviour. One particularly prominent sociopolitical theory is the Social Determinants of Health approach promoted by the World Health Organization (WHO) (Marmot 2005; WHO 2008). This approach is a broad analytical framework that seeks to identify the foremost social, economic, and political conditions—from government policy to the distribution of power, income, goods, and services—that determine the health of societies, social groups, and individuals (Dean and Fenton 2010; Kreiger 2001; Marmot and Wilkinson 2006). Including these social determinants in HIV and AIDS intervention analyses necessitates developing interventions that explicitly endeavour to redress social inequality, collective susceptibility and vulnerability.

Although varying slightly, what these structural models all share is an emphasis on moving beyond *identification* of disparities and constraints to actually *eliminating* them or mitigating their harmful effects. These structural approaches to HIV prevention can be differentiated from the paradigmatic behavioural interventions by their focus on directly alleviating the broader social, economic, political, or environmental factors affecting individual behaviour and determining HIV risk and vulnerability in particular contexts, *rather than merely addressing the behaviour itself* (Gupta et al. 2008, 766). These are long-term strategies, based on an appreciation that we cannot effect successful sustainable behaviour change in the long term without changing the underlying root causes and determinants of HIV risk and vulnerability, especially given the collective social vulnerability that many people experience (Gupta et al. 2008).

Structural approaches vary greatly depending on the distinct needs and circumstances

of any particular context, ranging from single policies or programs to holistic strategies that target many aspects of a social environment simultaneously, potentially including community mobilization processes, or policy or legal interventions (Dean and Fenton 2010; Kerrigan et al. 2006; UNAIDS 2010, 76). Comprehensive contextual analyses become very important in this sense, informing the design of tailored interventions, since there is no single blueprint for structural intervention that will work everywhere (Gupta et al. 2008). For example, interventions may be as diverse as initiating legal reform and creating policies on needle exchange, or developing microcredit programs for women to reduce vulnerabilities stemming from their economic dependence on men (Gupta et al. 2008, 766-8). In many cases, these interventions target factors entirely outside the domain of the health sector (in areas such as transportation, finance, education, or criminal justice systems) and these ‘non-health’ interventions often seem on the surface less related to HIV than to the realm of broad social change or development processes (Dean and Fenton 2010; Gupta et al. 2008; Rhodes 2002). However, as I have discussed above, these broader socio-structural aspects bear directly upon HIV vulnerability, and thus it is of paramount importance that HIV and AIDS communicators extend their analysis and scope of intervention to effect change in these other areas as well, in order to create a more enabling environment for HIV prevention.

These structural models are complemented by a number of specific gender- and culture-oriented strategies that attend to the complex dynamics of gender, sexuality, and culture vis-à-vis HIV intervention. As described above, gender-based inequalities impact HIV vulnerability, and hence many critics have advocated the need for gender to be situated as a central consideration in any response to the epidemic (Kalipeni et al. 2009; Susser 2009). For example, Gupta and Weiss (2009) have proposed an analytical framework for a gender-based response founded on tactics that seek to challenge gender and sexual stereotypes,

account for gender differences, transform gender roles and relationships, and empower women and girls. Culture, too, must be incorporated as central to the planning, implementation, and evaluation of HIV and AIDS intervention. Many scholars have long recognized that outreach and education relating to HIV and AIDS is also necessarily a process of *cultural* communication—not just health communication—and that culturally appropriate strategies are crucial, given the culture-specific codes and meaning of sexuality, family, morality, and social norms of behaviour (Airhihenbuwa and Obregon 2000, 8; Michal-Johnson and Bowen 1992; Swanepoel and Hoeken 2008).

Airhihenbuwa's "PEN-3" model is one such culture-centred strategy that has been used to guide HIV/AIDS interventions in African contexts (Airhihenbuwa and Webster 2004). The PEN-3 model features three domains of culture that must be examined in the development, implementation, and evaluation of any communications interventions for the epidemic: cultural identity, relationships and expectations, and cultural empowerment<sup>110</sup> (Airhihenbuwa and Webster). Likewise, Singhal (2003) has identified four elements of a culture-based approach to HIV/AIDS communication intervention: viewing culture as an ally, not a barrier; reconstructing cultural rites and practices; employing culturally resonant narratives; and creating a culturally based pedagogy of HIV prevention to stimulate collective action. The emphasis these models place on 'cultural empowerment' and the need to perceive culture as an 'ally' is vital to the pursuit of strengths-based approaches. Rather than adopting a risk-based perspective focusing primarily on negative behaviours and practices, these cultural strategies recognize positive cultural competencies and resiliencies and highlight the agency of local participants in developing context-specific and culture-centred communication interventions, fostering more community-based dialogical and

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<sup>110</sup> As Airhihenbuwa and Webster (2004) note, the term 'cultural empowerment' challenges the conventional coupling of culture with barrier and empowerment with strength.

participatory modes of health communication.

### 3.3.2 *A Human Rights Framework for Health Communication*

In addition to these broad-based holistic socio-structural, environmental, and cultural approaches, another specific sociopolitical framework is the ‘human rights’ approach to health. In general, the concept of human rights provides a powerful discursive and analytical ‘master frame’ for collective action which can be adapted to particular causes to draw attention to social justice issues and facilitate broad-based alliances, domestically and internationally (Johnson 2006; London 2008). This intrinsic understanding of human rights as a platform for achieving social justice offers a particularly useful context guiding responses to the social inequalities and structural factors constraining access to health. Hence, a number of health communication researchers and practitioners have contended that communication from a human rights perspective is highly pertinent to health interventions in general, and especially to HIV/AIDS programming (Ford et al. 2003; Gruskin et al. 2007; Johnson 2006; London 2008).

Human rights-based approaches have been widely adopted in global health policymaking, programming, and activism, particularly by those engaged in social epidemiological or structural analyses of health crises, and by those campaigning for enhanced access to ‘essential medicines’ (such as ARVs) and improved health services and facilities (White et al. 2009). Despite myriad differences in tactics and organization, the global AIDS activist community has generally been guided from the outset by a broad social justice agenda, in part fueled by its origins in the gay rights movement by and the intense discrimination against people living with HIV and AIDS (Mbali 2005). As a result, many AIDS activists have anchored their campaigns “in a fundamental belief in the human rights to health, dignity and self-determination” (Bass et al. 2008, 152). This tendency has been

mirrored by many states and international bodies, and now nearly all health organizations and development agencies publicly recognize the links between health and human rights in their work, and frame the exigency of HIV and AIDS intervention in human rights terms<sup>111</sup> (Barr et al. 2011; Gruskin et al. 2007, 450; Johnson 2006, 664; UNAIDS 2010, 121-44).

In this framework, individual prevention efforts and self-protection from HIV/AIDS is definitively placed within a broad social context, and governments and other interventionists are not perceived as having the capacity to change people's behaviour, but rather as having a duty to respect, protect, and fulfill the human rights of individuals and communities infected or affected by HIV and AIDS (Ford et al. 2003, 603). Not only does the fulfillment of health-related rights become a legal obligation of the state, but adopting this social justice perspective on health enables "a broad-based response to health and development by national and international stakeholders with responsibilities that reach beyond the health sector" (Gruskin et al. 2007, 451). In other words, the human rights framework is characterized by a keen understanding of the indivisibility of civil and political rights (such as freedom from discrimination) from socio-economic rights like the right to health and, in this context, access to AIDS prevention, treatment, care and support (Johnson 2006; London 2008). This conception fosters the socio-structural and environmental approaches discussed above, by establishing a legal context to hold duty bearers accountable, by stimulating the creation of policies and programmes that fulfill the human right to health in relation to AIDS, and by providing a powerful discursive tool legitimizing action to curtail the impacts of the epidemic.

Moreover, those who are infected or affected are not conceptualized as objects of charity; rather, they are rights-holders, and any communication interventions must recognize

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<sup>111</sup> The human rights-based framework for AIDS activism remains a prominent model in international AIDS discourses. For example, the XVIII International AIDS conference in Vienna, Austria in July 2010 convened under the theme of "Rights Here, Rights Now" (International AIDS Society 2010).

their agency, involve them, and empower them to realize their human rights to health and to a more enabling environment that mitigates HIV risk and impact (Ford et al. 2003, 603; UNAIDS 2010, 125). Agency is a central principle to a human rights framework, as London explains: “In order to address conditions that create vulnerability, a human rights approach must seek to give voice to those who are vulnerable and enable them decision-making scope to change their conditions of vulnerability” (2008, 68). Communication from a human rights perspective is thus implicitly associated with more participative modes of communication, moving beyond the mere dissemination of interventionist-dictated messages to facilitate dialogue and engender context- and needs-based responses to help local people negotiate change on their own terms.

The individual manifestations of human rights-based interventions are diverse and context-specific, but generally include efforts to hold governments and other organizations accountable, to develop legal policies and programs that ensure human rights, and to facilitate redress for those whose right to health has been violated (Gruskin et al. 2007; London 2008). With respect to HIV and AIDS communication interventions specifically, this involves both realizing the rights that mitigate vulnerable people’s risk of HIV infection, and enabling and protecting the rights of people living with HIV so as to ensure their dignity and social support and reduce stigma and discrimination (UNAIDS 2010, 122). One area in which the human rights-based framework has been widely adopted vis-à-vis HIV and AIDS is in the discourse and activist interventions surrounding the treatment access movement. The human right to health, in the context of AIDS, necessarily includes universal access to treatment.<sup>112</sup> As a result of human rights-based litigation and advocacy, as well as increased generic pharmaceutical production and competition, dramatic progress has been made over

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<sup>112</sup> In 2001 and 2003, the United Nations Human Rights Commission affirmed that, in the context of the AIDS epidemic, access to treatment is essential to realizing this human right to health (Schwartländer et al. 2006, 543).



the past decade toward universalizing access to ART, particularly in developing nations.<sup>113</sup> Moreover, while the goal of universal access to HIV *treatment* is indeed essential, Coates et al. remind us this human right of universal access must also extend to *prevention* as well, including access to the technologies, devices, information, skills and services for HIV prevention (2008, 679-80). This social justice perspective on health and HIV has been embraced by UNAIDS, reflected in their new vision of achieving “zero discrimination, zero new HIV infections, and zero AIDS related deaths through universal access to effective HIV prevention, treatment, care and support,” and explicitly positioning human rights a fundamental component of AIDS intervention (UNAIDS 2010, 7, 1212).

### 3.3.3 *Advocacy and Social Mobilization*

In attempting to foster broad-based social change—whether from a structural, gender, culture, or human rights perspective, or some holistic combination of these—many academics and practitioners have turned to advocacy communication as a strategy to address directly the myriad social, political, economic, and cultural factors impacting HIV and AIDS. This is a fundamentally different use of communication for public health purposes, targeting policies and institutions, not individuals, by intervening in and attempting to re-frame public discourse and debate on issues of importance to AIDS (Freimuth 1992, 104-105; Waisbord 2001, 23). Advocacy-based approaches to health communication are not new—critics of the dominant bio-behaviour models have been emphasizing the importance of advocacy for at least two decades—but these approaches have tended to be sidelined in mainstream

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<sup>113</sup> As noted in Chapter One, by 2011 the cost of ART in developing countries was just US\$61 per patient per year, down from tens of thousands a decade earlier, and this monumental progress in the affordability of treatment has resulted in dramatic increases in accessibility: by the end of 2009, about 36% (5.2 million) of people in need were receiving ART in low- and middle-income countries (MSF 2011; UNAIDS 2010, 95). However, international funding for AIDS has declined since 2009, jeopardizing the future of programs working toward universal access and leaving national programs, PEPFAR, and the Global Fund to Fight AIDS, TB, and Malaria critically short of resources (MSF 2011, 3). In November 2011, the Global Fund cancelled its next round of funding, leaving many AIDS programs and organizations in a dramatic funding crisis (IRIN 2011). It is clear that true ‘universal’ access is still a distant prospect, and the progress that has already been made is in serious peril.

responses (Crimp 1989; Freimuth 1992, 104; Lupton 1994, 63; Ratzan 1993, 5). It is beyond the scope of this thesis to explore this topic in any detail here, but it is important to acknowledge the vital role that advocacy has to play in effecting socio-structural change, as opposed to individual behaviour change, in responses to the AIDS epidemic.

Health communication is not only concerned with the health of individual members of society, but also, necessarily, with the health of communities and nations (Ratzan 1993, 5). Thus it is paramount that health communication responses to AIDS also employ tactics specifically designed to influence the sociopolitical forces that shape collective health. As with the other frameworks, specific advocacy communication tactics vary according to the situation. However, in the most general sense they involve the strategic use of mass media and other communication channels (including interpersonal communication) to advance a specific social cause. This may involve communicating arguments about the need for structural changes vis-à-vis AIDS, raising human and material resources for AIDS-related programs and services, influencing public opinion and perceptions, or attempting to gain the acceptance of, and commitment to, a program by social and political leadership (Lie 2008, 284; Lupton 1994, 63-64; McKee et al. 2004, 56; Waisbord 2001, 23). AIDS advocacy communication may be targeted at local, national, or international levels, and can be employed not only to strengthen political commitment and effect institutional and policy change, but also to raise awareness and understanding in order to combat social stigma and discrimination, to reduce victim blaming that has been too often prevalent in AIDS discourses, and to influence social norms in a given community, and thus create a more enabling social environment for HIV/AIDS intervention (Lie 2008, 284; Lupton 1994, 63-64; McKee et al. 2004, 55-62; UNAIDS/Penn State 1999).

This approach relies on a keen understanding of the power of discourse in shaping

social responses to illness and disease in general, and AIDS in particular. It seeks to combat the hegemonic discursive constructions of the epidemic that are detrimental to response efforts (such as the representations of African sexuality discussed above), and reframe oppressive mainstream discourses in a manner more productive to the design and implementation of effective intervention.<sup>114</sup> In attempting to accomplish these goals, many advocacy approaches to HIV and AIDS communication have adopted a human rights framework, as discussed above (Gruskin et al. 2007, 452). The powerful rights language lends itself well to reframing popular discourse on the epidemic, normalizing arguments for structural change as necessary to achieve fundamental human dignity, and legitimizing claims advanced by proponents to improve the accessibility and effectiveness of HIV prevention, treatment, care, and support services.<sup>115</sup>

Effective HIV/AIDS advocacy communication is also intrinsically entwined with the process of social mobilization, compelling the active response of diverse partners and generating support from multiple communities (McKee et al. 2004, 65-72). If the goal of advocacy communication is to “empower the public to participate more fully in defining the social and political environment in which decisions affecting health are made” (Freimuth 1992, 104), then communication strategies must seek to inspire individuals, organizations,

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<sup>114</sup> Lupton has noted the way in which AIDS advocacy groups such as the AIDS Coalition to Unleash Power (ACT UP) effectively re-shaped such oppressive discourses in the early years of the epidemic. Through aggressive lobbying for policy change, skillful engagement of the news media, and the sophisticated use of language, ACT UP reclaimed, at least discursively, the agency and humanity of those infected and affected by HIV; for example, they helped shift the terminology from “AIDS victims” to “people living with AIDS” (1994, 64).

<sup>115</sup> One particularly salient example of an AIDS advocacy organization explicitly, and successfully, adopting a human rights-based approach is South Africa’s Treatment Action Campaign (TAC), one of the longest-running and best-known social movements for treatment access worldwide. As exemplified by its launch on International Human Rights Day in 1998, TAC has unequivocally embraced this archetype, clearly situating access to AIDS treatment as a fundamental human rights issue, and as a result has achieved critical victories in South Africa, and influenced global thinking on the issue (Bass et al. 2008, 156; Friedman and Mottiar 2005; Makino 2009; Robins 2004). TAC’s alignment with the human rights-based approach to AIDS advocacy has been perhaps most evident in the organization’s involvement in the much publicized court cases fighting the pharmaceutical industry and its successful litigation against the Health Minister in South Africa’s Constitutional Court over the provision of prevention of mother-to-child transmission (PMTCT) programs in public health facilities. In these cases, TAC was able to employ a human rights framework as a powerful discursive tool to shame the government and overcome the powerful neoliberal interests of Western-based pharmaceutical companies, modifying their behaviour and ultimately improving access to medication. (For a more detailed description of this struggle, see Friedman and Mottiar 2005; Makino 2009; Mbali 2005; Nattrass 2007; Robins 2004.)

and communities to involve themselves in the movement.

Although participation is an important objective in its own right, and increased involvement of affected communities will contribute to the effectiveness and sustainability of HIV and AIDS interventions, as I argue below, social mobilization is also necessary to generate broad-based support that will ensure governments and other organizations are held accountable for their commitments to AIDS. Evidence suggests that without the mobilization of widespread civil society support, even legal approaches and human-rights based advocacy will not effect material change in health systems (Gruskin et al. 2007, 452; London 2008, 67-70; Makino 2009, 119-122). London (2008) argues that the treatment access movement, for example, would have lost its transformative potential had the court action not been grounded in extensive popular engagement. While some progress has been made in local African and international contexts to foster more effective and holistic AIDS intervention, it would seem that, particularly in the international development landscape, some structural changes are more difficult and intimidating to pursue because of the complex dynamics of economic imperatives and political agendas at play. Thus, advocacy communication and broad-based social mobilization will remain vital aspects of HIV/AIDS communication moving forward, complementing any efforts aimed at inducing behaviour change in individuals and communities.

### *3.3.4 Participation, Dialogue, and Empowerment*

Many of these alternative frameworks and approaches to health communication for HIV/AIDS have emphasized the importance of local participation in achieving successful, sustainable, and context-appropriate responses to the epidemic. As I have discussed in Chapter Two, scholars and practitioners of Communication for Development have underscored the need to strive for more participatory and dialogical methodologies. The same

is true for health intervention, and especially for HIV and AIDS. There has traditionally been considerable conflation of ‘communication’ and ‘education’ in health communication rhetoric, but most mainstream approaches have in reality offered very little genuine two-way communication (Lupton 1996, 56). Much greater emphasis has instead been placed on the unidirectional transmission of ‘educational’ messages, evidenced by the focus on mass media campaigns. Although mainstream implementations of BCC have sometimes been participatory to a degree, with members of the target audience involved in providing feedback during the formative research and pre-testing stages of design, this is a very limited form of participation (Ford et al. 2003; Lie 2008, 284-5; Quarry and Ramírez 2009; Waisbord 2001). For real change to occur, interventionists must move beyond disseminating top-down and expert-driven ‘messages’ to pursue truly dialogical approaches.

Local involvement in the design, implementation, and evaluation of communication interventions is essential so that the particular needs, priorities and social environmental contexts of local communities may be effectively accommodated (Coates et al. 2008, 67; Maibach et al. 1993, 29; Neuhauser and Kreps 2010, 12). Genuine dialogue is vital so that these communities may collectively develop their own capacity to change their social contexts fostering endogenous responses and harnessing cultural strengths (Ford et al. 2003, 604). Although international development discourses often pay lip service to the importance of community participation and ownership, in practice community involvement is seldom seen as the foundation of communication responses to HIV/AIDS (Ford et al. 2003; Green and Ruark 2011, 223-239).

Participatory-based communication approaches to HIV and AIDS intervention can also yield alternative modes of intervention that may be more effective. For example, in the peer education model prevalent in sub-Saharan Africa, lay people—ordinary members of

local communities or vulnerable groups who may be alienated from formal health service provision and intervention—participate and collaborate in HIV prevention efforts by educating and encouraging their family, friends, co-workers, and community members to adopt preventive practices and seek testing and treatment if necessary (Coates et al. 2008, 674; Dickinson 2009; UNAIDS 1999, 15). Peer education is a form of social mobilization and grassroots activism that is based on horizontal (rather than vertical) communication processes, is deeply embedded in local cultural contexts, and adopts face-to-face dialogical modes of communication between similar individuals who are conceptualized as agents, rather than targets, of change (Dickinson 2009, 6). As a result, this type of communication has proven valuable not just in stimulating behaviour change through collective action, but also in combating social stigma and collective constructions of beliefs about AIDS (Dickinson 2009; Hope 2003; UNAIDS 1999).

Participation and dialogue are especially important with respect to the design, implementation, and evaluation of culturally sensitive and gender-specific HIV/AIDS communication. Culture-centred approaches necessitate dialogue with cultural participants in order to achieve culturally appropriate and contextualized responses, locating the agency of these participants and their own enunciation of health issues as central to any intervention (Basu and Dutta 2009; Michal-Johnson and Bowen 1992, 168; Quarry and Ramírez 2009, 96). The need for participation extends to gendered responses to the epidemic as well, particularly for interventions addressing African women and girls: “While women have been counted and targeted for intervention, the recognition of women as significant actors and agents of transformation has yet to be fully documented...Although in southern Africa women are now the leading group living with AIDS (as well as the main care-givers and community activists), research on the strategies and agency available to women has lagged

behind many other considerations” (Susser 2009, 5). As Fuller explains, at the heart of many of the ‘solutions’ for HIV prevention (such as education, outreach, and behaviour change) is actually the basic issue of *empowerment* (2008, 175). Thus, participatory modes of engagement are paramount here. Communication must be harnessed to empower African women and girls to develop life skills and improve their capacities to enact their own agency, addressing the social, political, and economic realities that shape their lives and contribute to their HIV vulnerability.

However, what is perhaps most critical in the consideration of participation vis-à-vis AIDS intervention is the continued need for the central involvement of people actually living with HIV—as well as their families and communities who are so intimately affected—in the analysis, planning, implementation, and evaluation of any communication programs addressing the epidemic<sup>116</sup> (Simon-Meyer and Odallo 2002; UNAIDS 2007; UNAIDS/Penn State 1999, 64). As practitioners and researchers who are often external to the contexts we are examining, we risk disaffecting and distancing ourselves from the deeply human face of the epidemic. We must take care that both the infected and affected are intimately involved in any HIV/AIDS communication intervention, so that our responses are not only appropriate and specific, but may also achieve the necessary compassion and humanity to be truly effective.

### 3.3.5 *From Behaviour Change to Social Change: Calling for a Multi-level Approach*

With their emphasis on employing broad-based advocacy and empowering participatory frameworks in order to target the larger socio-structural, environmental, and

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<sup>116</sup> Since 1994, many organizations and practitioners have promoted and embraced the greater involvement of people living with or affected by HIV/AIDS—commonly referred to as the GIPA principle—as an integral component of ethical and effective AIDS intervention (Simon-Meyer and Odallo 2002; UNAIDS 2007). However, more recently, some groups have advocated the need for the meaningful involvement of people living with HIV (MIPA) to stress the importance of incorporating these participants as active and equal agents of change, and not merely token or peripheral contributors (Kim et al. 2012; UNAIDS 2007, 2).

cultural determinants of HIV vulnerability, as opposed to individual cognitive and behavioural factors, the above alternative models for health communication for HIV/AIDS in development contexts reflect a conceptual shift from health communication for *behaviour change*, to health communication for *social change* (Ford et al. 2003, 606; Lie 2008, 284-5; McKee et al. 2004). Indeed, this paradigmatic shift reflects a growing understanding amongst academics and practitioners that behaviour change for HIV prevention depends, in most instances, on concurrent change in the broader underlying social conditions that facilitate or inhibit behaviour associated with HIV risk. However, while the dominant behaviour change communication models are easily critiqued, and the need for broader socio-structural and culturally contextualized constructs is easily articulated in theory, we must recognize that the alternatives are often less straightforward in practical realization. Achieving full participation is a complex challenge—and is not always appropriate—and interventions designed specifically for local socio-political, economic, and cultural contexts are often more time-consuming and expensive than interventions based on the replication (with minor adaptation) of messages, materials, and programming developed in other contexts.

Moreover, the critiques I have presented above should not be taken as an outright rejection of the objective of changing behaviour, and the alternatives that I have highlighted should not be perceived as intrinsically opposed to the mainstream behaviour change models. Primary behaviour change, such as reducing the number of concurrent partners and delaying the age of sexual debut, has indeed proven a successful strategy in reducing HIV prevalence in some African countries (Green and Ruark 2011). Given the nature of transmission of the virus, the adoption of safer sexual practices (as well as harm reduction techniques) is a necessary and important part of curtailing the spread of the epidemic, and this undoubtedly involves changing behaviour. We must understand that it is not the notion of behaviour



change itself that is inherently problematic, but rather the way it has been implemented in the paternalistic, ethnocentric, and sometimes moralizing transfer of BCC techniques from very different cultural contexts, much like early development models based on modernization theory. Thus, while there remains a need to continue to pursue, theorize, and promote alternative modes of HIV/AIDS communication, these alternative structural approaches should be taken *alongside* (increasingly sophisticated) behavioural interventions, rather than replacing individually oriented behaviour change communication altogether (Coates et al. 2008, 669; Green and Ruark 2011, 177). Behaviour change communication can and should have a place in HIV/AIDS communication—when done participatively with local communities and grounded in culture and gender analyses—but only in concert with other methods like advocacy and social mobilization that target broader socio-structural conditions.<sup>117</sup>

Many scholars and practitioners have recognized that what is truly needed, then, are multi-faceted, multi-level analyses and approaches to HIV/AIDS communication intervention, integrating biomedical, behavioural, and socio-structural components (Coates et al. 2008; Dean and Fenton 2010; Friedland 2006; Gupta 2008; Lie 2008; McKee et al. 2008; Melkote et al. 2000). Although this may be true for many different health communication scenarios, it is particularly germane for HIV and AIDS: “No disease better exemplifies the inextricable bonds between biology, behaviour, and culture than HIV/AIDS, nor is any other more likely to break through and to transcend the boundaries that separate them” (Friedland 2006, S9). In an era of Highly Active Antiretroviral Therapy (HAART)—combination

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<sup>117</sup> Indeed, BCC models like social marketing and entertainment-education have the potential to be employed more comprehensively, such as the Soul City example from South Africa, which has embraced a human rights framework informing content and programming development and has attempted to mobilize audience communities (Goldstein et al. 2008; Quarry and Ram 2009, 109; Tufte 2008, 343). Although perhaps less common in realization, it appears that these strategies may actually lend themselves well to applications targeting many aspects of socio-structural and cultural environments, given their broad reach via mass media platforms.

therapy involving three or more antiretroviral drugs—we also need “Highly Active HIV Prevention,” incorporating a combination of prevention strategies<sup>118</sup> (Coates et al. 2008, 670; Holmes 2007, 520). Recognizing this need for more comprehensive and multidimensional approaches, UNAIDS has recently begun to promote “combination HIV prevention,” as the best hope for achieving substantial and sustained reductions in HIV incidence (Kurth et al. 2011; UNAIDS 2010b). According to UNAIDS, “combination prevention relies on the evidence-informed, strategic, simultaneous use of complementary behavioural, biomedical and structural prevention strategies...[that] operate on different levels (e.g., individual, relationship, community, societal) to address the specific, but diverse needs of the populations at risk of HIV infection” (2010b, 5).<sup>119</sup>

Embracing a holistic multi-level strategy involves taking into account theories explaining behaviour at all levels and integrating these explanations with perspectives on the social determinants of health, the cultural and gendered facets of the epidemic, and a sensitivity to stigma and discrimination. It necessitates the development of comprehensive responses targeting underlying socio-structural conditions and fostering enabling environments. It also involves embracing endogenous strategies and cultural strengths, incorporating participation of local communities in planning, enacting, and reflecting on interventions, and mobilizing these communities to action through advocacy communication. By any measure, this is a formidable task, presenting a host of political, sociocultural, and logistical challenges to implementation. Yet it also holds the promising potential to

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<sup>118</sup> As Coates et al. describe, Highly Active HIV Prevention encompasses both leadership and scaling-up of treatment and prevention efforts and community involvement, and incorporates a combination of behavioural change, biomedical strategies, treatment (ARV/STI/antiviral), and social justice and human rights (2008, 670).

<sup>119</sup> More specifically, UNAIDS identifies six key features of combination prevention, consistent with the multi-level approach I discuss here: 1) carefully tailoring interventions to local need and conditions; 2) including a strategic mix of structural, biomedical, and behavioural approaches to address the specific needs of target groups, focusing on the immediate risks as well as the underlying causes of their vulnerability; 3) planning interventions synergistically and consistently over time to address multiple levels; 4) prioritizing investments with the engagement of affected community, as well as mobilizing community, private sector, government, and international resources; 5) requiring, benefiting from, and investing in partnership and coordination in program design, resourcing, and management; and 6) incorporating flexibility so as to permit ongoing assessment and improvement of strategies, and adopting new tools and approaches (UNAIDS 2010b, 13).

accommodate the inherent complexity of the epidemic, and intensify much-needed global prevention efforts (Piot et al. 2008). The great value of this potential demands that these comprehensive combination approaches must be pursued, no matter how difficult their realization.

Lie (2008) has suggested that, rather than attempting to develop some sort of encompassing theory or model to guide such holistic responses, what is more helpful is to develop broad sets of flexible conceptual frameworks and common principles to guide intervention. Such frameworks would serve not to instruct interventionists to follow a particular pre-determined model, but rather to offer central concepts informing the development of a particular response<sup>120</sup> (Lie 2008, 287). Although perhaps theoretically ambiguous and conceptually vague, this flexibility means that such frameworks will necessarily be dialogue-based and context-specific in their enactment, which can only strengthen communication responses to HIV and AIDS.

### **3.4 Beyond Prevention: Communication and the AIDS Continuum**

I have thus far focused predominantly on communication as it applies to HIV prevention, education, and awareness. This reflects the bulk of health communication interventions, theory, and discussion pertaining to HIV and AIDS. Since there is still no cure and no vaccine for HIV, much of the global effort to curtail the spread of the epidemic has been focused on education, awareness, and motivation of behaviour change involving adoption of preventive practices, as the best hope to control the spread of the virus (Airhihenbuwa and Obregon 2000, 5; Freimuth 1992; Melkote et al. 2000). Indeed, communication is central to prevention efforts, and widespread awareness and education

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<sup>120</sup> For example, Lie suggests that such a framework might encompass concepts such as gender, sexuality, power, stigma, risk, religion, parenthood, livelihood, and many others, depending on the particular local situation (2008, 289). He also cites UNESCO's 2004 checklist of common principles or facets of effective HIV/AIDS projects or programs: cultural-appropriateness, respecting human rights, gender- and age-responsiveness, and involvement of people living with HIV and AIDS throughout the intervention process (qtd in Lie 2008, 292).

remain crucial in order to limit further spread of the virus. Yet the role of communication in AIDS intervention need not end there. Communication offers us a variety of more complex possibilities—or, more accurately, imperatives—vis-à-vis HIV and AIDS in many dimensions of intervention, from initial outreach through to palliative care. However, research, policy, and programs that have acknowledged the role of health communication in ‘treatment, care, and support’ have seldom gone beyond a cursory mention, and hence the particular dynamics, possibilities, and challenges of developing these non-preventive communication interventions have been left largely untheorized.

There is a great need for communication-centric approaches to developing strategies and programs addressing the full HIV/AIDS continuum, which encompasses not only prevention outreach and education, but also testing, treatment, care, and support (Bharath-Kumar et al. 2009; Fuller 2008; McKee et al. 2004). “This continuum involves planning and program implementation on a sustained, coherent, and long-term basis within various phases of HIV/AIDS through prevention, care, support, and management of the disease” (Airhihenbuwa et al. 2000, 102-3). To begin with, this means employing communication interventions to address the broad range of socio-structural determinants of HIV vulnerability and nurture HIV-related advocacy, as I have already elucidated above. For example, this involves awareness, community engagement, and empowerment initiatives to combat stigma, reduce discrimination, promote disclosure, and encourage peer support, and thus create more enabling environments (McKee et al. 2004; Nambiar et al. 2011). However, reassessing the role of health communication in the landscape of HIV and AIDS also means recognizing the indispensable role that communication interventions might play in supporting and strengthening the effectiveness of an expanded range of social and clinical services. This role necessarily includes shaping knowledge and perceptions of, generating demand for, and

improving access to AIDS-related services such as: promoting testing (VCT); facilitating access to treatment (including PMTCT) and improving adherence; enhancing client-provider/doctor-patient interaction; and providing care and social support to people living with HIV (Bharath-Kumar et al. 2009; McKee et al. 2004, Nambiar et al. 2011). Particularly in the African context, communication can also enable and accommodate the frequent reliance on non-professional medical personnel<sup>121</sup> such as community health workers (CHWs)<sup>122</sup> to provide outreach, treatment, and support services (Iluyemi 2009). Indeed, communication for HIV/AIDS initiatives should be conceived not as a set of isolated activities or campaigns to be carried out by communication ‘specialists’ but rather as an integral facet of the entire intervention process, recognizing that communication perspectives are thus central to all domains of AIDS intervention, not just the design of prevention messages and programs (McKee et al 2004, 53-54).

The widespread emphasis on prevention communication is in part a legacy of the era when AIDS was an immediate crisis with no treatment options—prevention was the only hope for saving lives—but now that HAART is more affordable and increasingly widely available, treatment and care have become more central aspects of AIDS intervention. ART adherence is a vital issue, especially in developing countries where minimization of the need for more expensive second- and third-line regimens is a serious economic imperative, and one that has significant potential to be addressed through communication intervention

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<sup>121</sup> Severely overstretched health systems in many African countries—and an acute lack of health professionals and hospitals beds—means that many people living with HIV are receiving care in their homes, either informally from family and neighbours, or frequently through more structured community Home Based Care organizations. Such grassroots organizations are vital in filling health care gaps, providing services as diverse as dispensing drugs and food, providing counseling and nutrition information to clients and their family members, monitoring treatment adherence, making referrals to clinics and other service providers, assisting with accessing social assistance and grants, bathing and feeding clients, helping with household chores, and providing palliative care and companionship to people in the advanced stages of AIDS.

<sup>122</sup> CHWs are also sometimes referred to as community-based health workers (CBHWs) or peer health workers (PHWs). In South Africa alone there are more than 70,000 CHWs in the health sector, and they perform a vital range of health services, especially in more rural and remote areas where travel distances to health clinics are prohibitive (Leon and Schneider 2012, 2). While these workers are trained for the health intervention they are a part of, they have no formal certification or tertiary education in the field (Lewin et al. 2010). CHWs are overwhelming women, usually unpaid and often HIV positive themselves. Supporting them is of paramount importance in AIDS intervention in Africa (Iluyemi 2009).

(Bharath-Kumar et al. 2009; Friedland 2006). Traditionally, prevention has been seen as the domain of HIV/AIDS communication, whereas treatment was the domain of biomedicine; this perspective must be challenged, so that we may adopt a more holistic and nuanced understanding of ‘treatment’ in the context of this epidemic.<sup>123</sup>

As Bharath-Kumar et al. (2009) have persuasively argued, this means moving beyond the ‘medical model’<sup>124</sup> of ART rollout, recognizing the myriad societal influences beyond the clinical setting that bear upon treatment effectiveness, and harnessing complementary communication channels to overcome barriers to accessing services and maintaining ART adherence. They have proposed a series of five stages of ART (from asymptomatic infection with serostatus unknown, through to advanced treatment in the late stages of AIDS illness), each accompanied by its own specific communication needs and objectives (Bharath-Kumar et al. 2009, 449-50). Moreover, they contend that communication in the rollout of ART must look beyond the seropositive individual to direct communication interventions at family members, service providers, caregivers, the general public, policymakers and community leaders (Bharath-Kumar et al. 2009, 450-51). An enabling environment fostered by strong familial and community support mechanisms (such as interaction with CHWs and treatment support groups) has shown both immediate and long-term positive impacts on ART adherence (Wouters et al. 2009). Just like HIV transmission, HIV treatment is a social activity with social determinants, and thus communication interventions aimed at improving access and adherence to HIV testing and treatment programs must seek to influence these

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<sup>123</sup> At the same time, we cannot divorce treatment adherence from prevention efforts, given the role we now know that ART has to play in preventing transmission. HIV treatment has recently been proven to lower the likelihood of transmission in discordant couples by up to 96%, and thus can be considered a form of prevention in its own right (El-Sadr et al. 2011). However, this a component of, rather than an alternative to, the combination prevention approach discussed above, since the availability of ART alone will not curb the epidemic, especially given how much remains to be accomplished to achieve universal access to treatment (Barr et al. 2011; Kurth et al. 2011).

<sup>124</sup> This medical model has been the primary focus in establishing and expanding ART internationally, and it encompasses ensuring drug supply to health facilities, training clinical staff, and delivering these services to people in need (Bharath-Kumar et al. 2009, 447-448).

social support networks, as well as individuals, well beyond the confines of the clinical setting.

Clearly, then, health communication for HIV and AIDS must champion communication-centric approaches for all aspects of the broader spectrum of HIV and AIDS intervention, recognizing the full range of applications in which communication can be employed strategically to address the epidemic. As the following chapters will explore, new ICTs—particularly mobile phones—present considerable opportunities in this respect, especially in development contexts. New technologies which are more interactive and less constrained by geography are, I argue, very useful in prevention intervention. However, they also afford equally compelling applications in communication interventions for these *other* facets of the AIDS continuum which have been addressed only superficially in most instances to date. Such applications include fighting stigma, improving treatment and medication adherence, reducing social alienation, and improving AIDS-related care and support systems to foster more enabling environments for positive living. The remainder of this thesis will examine these possibilities, and explore the particular nuances and challenges of such interventions in African contexts.

## **PART TWO: APPLICATIONS AND ANALYSIS**

### **--- CHAPTER FOUR ---**

#### **FROM THEORY TO APPLICATION: MHEALTH INTERVENTIONS FOR HIV/AIDS IN DEVELOPING NATIONS**

The previous two chapters have constructed a theoretical framework for mHealth, contextualizing and historicizing this supposedly ‘new’ phenomenon as a part of a long history of ICT4D and health communication interventions, and analyzing the limitations of dominant approaches to both ICT4D and HIV/AIDS communication in development contexts. With this theoretical foundation established, we can begin to explore specific, concrete applications of mobile phones for addressing HIV and AIDS in developing nations. The remainder of this thesis, then, is concerned with articulating both the promise and the potential pitfalls of developing mHealth applications to advance HIV/AIDS intervention in sub-Saharan Africa. This chapter will delineate those possibilities and highlight the range of applications for mobile phone-based HIV/AIDS communication. Chapter Five will draw on an in-depth case study to examine some of the complexities inherent in employing mobile phones for communication for health and development.

In this chapter, I will begin by briefly addressing the implications of new communication technologies for the field of health communication, especially in terms of the more interactive and participatory modes of engagement that may be facilitated by the use of these technologies. Situating mHealth as the point of convergence between the two bodies of theory examined in the previous two chapters, I will focus in particular on the implications of mobile telephony for health communication theory and practice, discussing the current landscape of the field of mHealth, what makes mobile such an attractive communication platform in HIV and development contexts, and how the growing hype and rapidly



proliferating pilot projects have not necessarily been accompanied by evaluation and evidence demonstrating efficacy or efficiency of these interventions. I will then survey the range of specific opportunities presented by the integration of mobile phones into HIV/AIDS work, as identified by media, policy, and academic discourses on mHealth. This diverse scope of mHealth applications that have been designed and implemented vis-à-vis HIV/AIDS and development contexts includes both applications integrated into the health sector itself, such as data collection and support for frontline health workers; and those directly engaging with the general population to connect citizens with health information, services, and treatment support, from mass prevention and education messaging to communication oriented toward encouraging HIV testing and ART adherence. However, given the emphasis of this thesis on communication-based responses to the AIDS epidemic, I will focus here specifically on those applications which leverage mobile phones as instruments for health communication with citizens and communities, improving their access to HIV-related information and services. Finally, I will briefly consider the ways in which many of these mHealth applications can be understood as continuations of the behaviour change communication discussed in the last chapter.

#### **4.1 ICTs and HIV/AIDS Communication: From eHealth to mHealth**

The rapid technological advancement and proliferation of ICTs over the past two decades has undoubtedly created new opportunities for health communication, and necessitated the development of new strategies and approaches to seize those opportunities. Health communication scholars and practitioners have exhibited a growing awareness and interest in the significant impact of new communication technologies—especially the Internet—in shaping the field, creating unprecedented new opportunities for engagement, and dramatically expanding the reach, convenience, and utility of health information and

behaviour change communication<sup>125</sup> (Owen et al. 2002; Parker and Thorson 2009; Wright et al. 2008). One of the primary perceived advantages of new communication technologies is their potential to open new spaces for more interactive forms of health communication, alongside more traditional one-way health education and information dissemination (Neuhauser and Kreps 2010; Owen et al. 2002; Ratzan 2002). These interactive capabilities, not possible with print and broadcast media, allow individuals to access pertinent health information more quickly and conveniently, enable health communicators to take advantage of the capacity for individualized tailoring and customization of health messages to create communication that is more personalized and contextual, and facilitate communication simultaneously across mixed media channels (Haider et al. 2009, 388; Neuhauser and Kreps 2010, 15-16; Owen et al. 2022, 514; Winchester 2009, 10; Wright et al. 2008, 12). This flexibility is especially appealing for communication about diseases like HIV, where private, anonymous, and personalized access to sensitive information may be especially desirable. For example, if individuals can access information about HIV and learn about risk-reducing behaviour by reading a website in private, or engaging in anonymous telephone or computer-mediated counselling, they may be more inclined to do so than if it means visiting a clinic in their community and asking potentially embarrassing questions.

This interactivity also affords the potential to develop more participant-centred and dialogical approaches to health communication, with feedback and participation built into the communication model. Ratzan (2010) suggests that new communication technologies (including mobile phones) present an opportunity to move beyond the tired IEC (Information, Education, and Communication) approach, to embrace something he calls IHC: Interactive

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<sup>125</sup> Of course, critical perspectives have also highlighted the ability of emergent technologies to impact health care negatively as well as to generate these more positive outcomes. For example, in addition to issues stemming from inequities in access, scholars have also noted issues around cost, literacy, credibility, privacy, and security of information (Matusitz and Breen 2005; Neuhauser and Kreps 2003; Owen et al. 2002; Wright et al. 2008, 156-166). I will explore some of these issues, as they apply specifically to mHealth communication, in Chapter Five.

Health Communication.<sup>126</sup> He argues that the IHC approach represents significant progress in global health communication, since it not only capitalizes on the increasing reach of communication technologies as enablers and linking agents between governments, citizens, and health systems, but it also fosters a shift toward citizen-centred health systems and the development of health-literate publics who are more empowered and involved in health decisions and treatment (Ratzan 2002, 2010). Although there are no doubt limitations to participation, as I will discuss below, the enhanced capacity for engagement afforded by such technologies as the Internet and mobile telephony mean that IHC applications do represent significant potential for realizing some of the alternative dialogue-based and context-specific frameworks for health communication discussed in the previous chapter.

#### *4.1.1 The Rise of eHealth*

For at least the past decade, the practice of integrating ICTs with health systems has commonly been referred to under the umbrella category of “eHealth” (Eysenback 2001). Although there remains a lack of consensus on the precise meaning of the term—in 2005, Oh et al. identified 51 unique definitions—it generally refers to the use of ICTs in support of health and health-related fields, including health education, communication, care, and research (Kwankam et al. 2009, 251; WHO 2005, 121). The field of eHealth thus encompasses applications like telehealth/telemedicine;<sup>127</sup> computer-mediated communication and knowledge sharing between providers, patients, and their communities; and computer-assisted learning, diagnostics, and monitoring (Neuhauser and Kreps 2010, 14). Yet in considering the impact of eHealth in developing countries, it is clear that its potential has

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<sup>126</sup> Ratzan explicitly positions mHealth as a leading development in the pursuit of more interactive health communication in a global context, given its potential to extend health information and services to people in remote areas and promote citizen-centred approaches to health care and well-being (2010, 692-3).

<sup>127</sup> “Telemedicine” is defined as the delivery of health care or the sharing of health information over a distance, using telecommunications (Kaplan 2006, 2). Some writers prefer the term “telehealth” to refer to broad applications like health education or the dissemination of health-related information (Foster 2010, 44).

been critically constrained by the limited reach of many of the communication technologies upon which these eHealth applications are based. Browsing health websites like WebMD.com, while immensely popular in the West,<sup>128</sup> is beyond reach of many citizens in less developed parts of the world, where critical socio-structural and economic barriers include high costs, lack of literacy and technical skills, uncoordinated health systems, and inadequacies or absence of the ICT infrastructure necessary to provide access (Haider et al. 2009; Ojo 2006; Ruxwana et al. 2010). The digital divide remains a considerable issue for eHealth globally: the lack of computer and Internet penetration in developing nations limits the reach and efficacy of digital communication technologies as instruments for health communication in these nations, and inequities in meaningful access to eHealth technologies potentially contribute to further health care disparities (Owen et al. 2002).

However, at the same time, many important stakeholders in international health and development have often positioned eHealth as a solution to some of the developing world's health challenges—mirroring the mainstream discourse and promotion of ICT4D more broadly. These eHealth proponents have advocated for the integration of ICT and health policy in developing nations so as to leverage the growing diffusion of communication technologies in order to bridge gaps and global inequalities in access to biomedical health innovations (Chetley 2006; Dentzer 2008; Dzenowagis 2009; Mars and Scott 2010). WHO, in particular, has spent considerable resources promoting eHealth as an important part of the solution for global health inequalities, and has established the Global Observatory for eHealth, an initiative designed to guide international policy and practice by promoting, researching, and reporting on eHealth strategies and best practices (Kwankam et al. 2009; WHO 2007). From this perspective, eHealth is explicitly perceived as an important strategy

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<sup>128</sup> For example, a national survey found that the majority of Americans turn to the Internet *first* for health information, rather than to a traditional health care provider (Hesse et al. 2005).

for addressing health-related development challenges, as explained in the consensus statement of the 2011 WHO Global eHealth Evaluation Meeting:

eHealth can help realize health gains and contribute toward transformational health system change...Used appropriately, eHealth has the potential to catalyze, support and monitor health improvements at scale, and to accelerate achievement of national and global development goals, including the United Nations Millennium Development Goals. (WHO 2011)

Although influential organizations like WHO have prioritized eHealth and the governments of many developing nations have moved to establish national eHealth strategies, many eHealth applications that depend on computers and the Internet continue to be of limited applicability to health communication theory and practice in development contexts.

#### 4.1.2 *The Special Appeal of mHealth*

One particular subset of eHealth that does offer particular promise for development contexts is mHealth. Health applications that specifically draw on mobile communication technologies hold enormous potential for regions with high mobile penetration, even where fixed line telephony, computers, and Internet access remain very limited, as is the case in much of the developing world (ITU 2011b; Kaplan 2006; Mechael 2009). Of course, mHealth is an area of intense hype, investment, and rapid technological development in high-income countries, too. There is no doubt that this is big business, and mobile operators, as well as equipment manufacturers and software developers like Google, Apple, and Microsoft, are scrambling to get a share of both markets. This is evidenced by exponential growth in both consumer- and clinician-oriented mHealth applications,<sup>129</sup> mostly developed for smartphones, PDAs, and other high-end mobile technologies.<sup>130</sup> However, the question, as

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<sup>129</sup> Industry research reports predict US \$1.3 billion in global revenue for mHealth applications in 2012 (Jahns and Gair 2012). Other reports indicate that 600 million mobile health applications are expected to be in use by the end of 2012, and there is room for significant future growth, with an estimated 70% of people worldwide interested in accessing mHealth applications and willing to pay for them (Lewis 2011). By August 2012, Apple is expected to offer more than 13,000 health-related iPhone applications for consumers and 6,000 medical applications for health care professionals (Gullo 2011).

<sup>130</sup> The mHealth market in developed countries also encompasses the development of mobile wearable body sensors and other related health surveillance technologies for wireless patient monitoring (Istepanian et al. 2004).

always, is how to ensure that these technologies can be leveraged for social good and that the health benefits of mobile phone applications do not extend only to the wealthiest populations or countries. In this respect, while mHealth is certainly an exciting and rapidly developing field globally, it is important to recognize that the most significant potential gains to be derived from mobile phone use in the health sector may actually have little to do with the types of flashy consumer smartphone applications that are being promoted in the marketing-driven hype circulating in mHealth discourses in the West. In developing countries where the health challenges are greater, the resources are fewer, and other ICTs are less accessible, the most compelling case for mHealth may lie instead in simple applications for low-cost handsets with only straightforward voice and text transfer capabilities (Mechael 2009).

In some ways, mHealth closely follows from telemedicine, and can be interpreted as the latest development in a range of eHealth innovations. However, in other respects it holds promise far beyond the scope of earlier telemedicine solutions, as there are a number of unique attributes of mobile phones that make them particularly well-suited for application in health and development contexts. The most obvious advantage of mobile telephony is its wide reach: with nearly 80 mobile cellular subscriptions for every 100 inhabitants in developing countries (compared to approximately 11 fixed telephone lines, and 26 Internet users), it is vastly more pervasive in development contexts than any other communication technology (ITU 2011b). Specifically in Africa, the distribution levels of fixed phone lines and Internet connectivity are even lower (penetration rates of 1.4 and 12.8<sup>131</sup>, respectively),

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<sup>131</sup> As noted in Chapter One, the penetration rate of Internet users in Africa can be somewhat misleading, since many of these users access the Internet only through community telecentres and Internet cafés, which offer a marked difference in meaningful access than a personally-owned and always-accessible technology. By the end of 2011, only just over 5% of Africans had Internet access in their homes, with many of these users concentrated in urban centres and wealthier nations like Mauritius, Seychelles, and South Africa (ITU 2011b). However, this situation is beginning to change as more Africans are getting online via their mobile phones. Many developing countries have been able to use mobile-broadband services to overcome infrastructure barriers associated with providing high-speed Internet access, especially in remote areas, and in Africa four times as many people now access broadband Internet connections via mobile phones than through a fixed line (ITU 2011c).

yet mobile phone penetration had already reached 53% by the end of 2011 and continues to increase rapidly, at a rate of almost 20% annually for the past five years (ITU 2011b; Mansfield 2011).

The particular attributes of mobile phones that have contributed to this ubiquity also make them especially appealing tools for health communication in low-income countries and other remote or resource-constrained settings. These functional and socio-structural features include: portability, sturdiness, ease of maintenance (including a non-reliance on electricity<sup>132</sup>), low-cost of start-up and affordability relative to other ICTs, flexible payment plans (such as pre-paid/pay-as-you-go service), and an increasing range of voice, text, and data transfer capabilities that afford immediate, continuous, two-way communication from any location, including isolated or remote locales<sup>133</sup> (Déglise et al. 2012; Free et al. 2010; Leach-Lemens 2009; Mechael 2009). The capacity for voice as well as text and visual communication possibilities (including the increasing prevalence and affordability of handsets with multimedia and Wireless Application Protocol [WAP] functionalities to access the Internet) allows users to communicate and share information among people with widely varying levels of literacy, which may be an important consideration in health and development communication contexts (de Tolly and Benjamin 2012; Mechael 2009). Mobile phones are also a predominantly personal and private technology—important for communication about sensitive or potentially stigmatized health issues like HIV—and offer quick transfer of individually tailored information and reminders (such as to take medication

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<sup>132</sup> In communities without access to electricity, mobile phones are often charged from car batteries or solar panels.

<sup>133</sup> In addition, some research suggests that the lines of communication via mobile networks may be less disrupted during times of crisis and displacement, making them useful tools for maintaining health communication in times of emergency or social upheaval (Mechael et al. 2010, 45-52). For example, in Kenya during the political crisis and widespread violence and displacement in 2008, 211 of 267 ART patients enrolled in one program could still be reached on their mobile phones just after the peak of the upheaval, mitigating some of the negative impacts and disruptions to HIV treatment during the crisis (Lester and Karanja 2008). Another study has demonstrated the benefits of using mobile phone SIM cards to improve disaster and epidemic outbreak response efforts by tracking population movements following the 2010 earthquake and cholera outbreak in Haiti (Bengtsson et al. 2011).

or attend medical appointments), as well as ongoing interactive communication and feedback that is beneficial for chronic care, especially in support of decentralized health systems and those that depend on community health workers (CHWs) (Fjeldsoe et al. 2009; Kaplan 2006; Mechael 2009; Winchester 2009). In addition, these tools can be used for data collection on the projects where they are deployed, effectively leveraging mobile capabilities for research study design to measure outcomes and usage of mHealth services (Mechael et al. 2012; de Tolly and Benjamin 2012).

#### *4.1.3 The Rush to Adopt mHealth*

Given these attributes of mobile telephony and their potential benefits for use in health and development contexts, the promise of mHealth for the developing world has generated immense attention and excitement in scholarly, policy-oriented, and mainstream media discourses alike, as the idea of using mobile phones to deliver health information and services and strengthen severely constrained health systems in developing countries has seemingly captured the imaginations of academics, technology developers, entrepreneurs, governments, and development funding agencies. Just as in mainstream ICT4D discourse, much of this discussion around mHealth for development has been characterized by some degree of technological determinism, utopian rhetoric about the ‘revolutionary’ implications of mobile technology in health contexts, and claims that developing countries can ‘leapfrog’ to advanced mHealth systems and personalized medicine (Economist 2009; GSMA 2012; Waegemann 2010). This perceived potential has been reflected in the remarkably rapid proliferation of literature, conferences, summits, webinars, pilot projects, and collaborative partnerships devoted to advancing mHealth in low-income countries, especially since 2009 (Anta et al. 2009; Kahn et al. 2010; Leach-Lemens 2009; Mechael et al. 2010; Ranck 2011; Vital Wave 2009; WHO 2011b). Many important stakeholders in fields of global health and



development<sup>134</sup> are now involved in this burgeoning field of mHealth adoption and experimentation, demonstrating their support with reports, white papers, and policy briefs, and by funding and implementing new projects in the Global South.<sup>135</sup> An important agenda-setting and coordinating force in this work has been the mHealth Alliance, founded in 2009 by the United Nations Foundation, the Vodafone Foundation, and the Rockefeller Foundation, which works to advance mHealth initiatives in low-income countries through advocacy, policy research, and support for practitioners and other stakeholders in the field (mhealthalliance.org). Later that same year, the mHealth Working Group was established as a collaborative forum for practitioners and researchers to share and synthesize knowledge and experiences with implementing mHealth projects in resource-poor settings, coordinated through monthly meetings, a listserv, and other collaborative activities (mhealthworkinggroup.org). In less than three years, the group has grown from just 20 members in Washington, D.C., to an international community of more than 700 members (including myself) in 35 countries, exemplifying the overall escalation of interest, research, and activity in mHealth for development.

#### *4.1.4 Searching for Evidence in a Nascent Field*

With mHealth firmly on the agenda of the international health and development community, it is no surprise that there has been an explosion of pilot projects, attempting to demonstrate in practice what is now widely accepted in theory: the *potential* for mHealth to make a significant impact in development contexts. Indeed, it is clear that the ‘case’ for mHealth in developing countries has been well-established, and there have certainly been

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<sup>134</sup> Examples include the UN, WHO, United States Agency for International Development (USAID), PEPFAR, Johns Hopkins Center for Communication Programs, Population Services International (PSI), and the World Bank.

<sup>135</sup> For example, a recent large-scale mHealth project aimed at the developing world is “MAMA” (the Mobile Alliance for Maternal Health), a partnership between USAID and Johnson & Johnson that was launched in 2011 with supporting partner the UN Foundation. MAMA is a US \$10 million investment in mobile phone-based communication systems to provide information and support to mothers in Bangladesh, India, and South Africa in order to help improve maternal and newborn health outcomes, and to support initiatives in other countries, through the provision of free, adaptable text and audio content (<http://healthunbound.org/mama/>).

successes—examples of well-implemented projects garnering positive results—as I will discuss below. However, despite this sudden abundance of pilots, there remains a paucity of critical evaluation and analysis as to the actual impact or value of these initiatives. There is certainly no shortage of literature on mHealth—a 2010 review identified nearly 3,000 peer-reviewed and secondary sources, mostly from the computer science, health informatics, and public health disciplines (Mechael et al. 2010). Yet numerous scholars, practitioners, and other stakeholders continue to lament the dearth of actual results measurement in mHealth literature, especially in terms of health outcomes and cost-effectiveness, and especially from developing countries<sup>136</sup> (Déglise et al. 2012; GSMA 2012b; Gurman et al. 2012; Leach-Lemens 2009; Mechael et al. 2010; Schweitzer and Synowiec 2012; Thirumurthy and Lester 2012). Although there has been some of this type of formal evaluation,<sup>137</sup> these studies are the minority,<sup>138</sup> and most of the limited evidence produced has come from research focused on high-income countries, on interventions for issues like smoking cessation, depression, diet/exercise, hypertension, and diabetes management, and with results not necessarily applicable to initiatives in developing nations nor to health issues like HIV (Cole-Lewis and Kershaw 2010; Fjeldsoe et al. 2009; Free et al. 2010; Kaplan 2006; Mechael 2009). For interventions in the developing world, most of the evidence has been anecdotal, and pertaining to the results of a multitude of small-scale, limited scope, short-term pilot or proof-of-concept projects, rather than through formal evaluation or long-term, large-scale studies (Déglise et al. 2012; Foster 2010; Kahn et al. 2010, 253; Kaplan 2006; Mechael et al. 2010; van Heerden et al. 2012).

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<sup>136</sup> This is not only true for mHealth, but also to some extent for eHealth more generally, which has also been criticized as having an inadequate evaluation of health outcomes and cost-benefit analysis (Catwell and Sheikh 2009; WHO 2011).

<sup>137</sup> For example: Chang et al. 2011; Chib et al. 2012; de Tolly et al. 2012; Lemay et al. 2012; Lester et al. 2010; Pop-Eleches et al. 2011.

<sup>138</sup> A recent global survey conducted by WHO found that 83% of countries have at least one mHealth project, but only 12% reported efforts to evaluate these mHealth activities (and only 7% of developing countries conducted any evaluation) (WHO 2011b, 9-10, 71-72).

This limited scale and scope of mHealth implementation and evaluation in developing countries means that the body of mHealth literature at present is lacking the evidence necessary to justify the investment of industry, governments, and donor organizations to take initiatives to scale and achieve broader enduring change (Mechael et al. 2010; Schweitzer and Synowiec 2012). As a result, the mHealth landscape has been impaired by what many practitioners have referred to as “pilotitis” (Germann et al. 2011; Text to Change 2010) or “pilot syndrome” (Déglise et al. 2012, 16), characterized by a plethora of relatively small, isolated pilot projects, many of them successful, but few of which are sustainable or scalable.<sup>139</sup> Sherry and Ratzan suggest that this situation is somewhat characteristic of such a “still nascent field,” where “in the early days of innovation, design, and new programming, anecdote commonly precedes evidence” (2012, 1-2). In some respects, such anecdote amounts to the “enthusiastic proliferation of untested methods,” which lack policy coordination, scale, or sustainability (van Heerden et al. 2012, 393). Sometimes, it might also amount to marketing hype of the mobile technology industry, with technological innovation driving adoption so that a profusion of products, services, and technologies are presented in search of a problem, instead of the other way around. Certainly we have seen this in the West, as mobile operators and health technologists compete to bring products to the growing consumer market.

Some scholars and practitioners have argued that a rapidly advancing field like mHealth actually demands alternative and more flexible modes of evaluation to the traditional long-term randomized controlled trial (RCT) and other ‘gold standards’ of scientific testing (Greenhalgh and Russell 2010; Mechael et al. 2010, 64). Given the rapid pace of technological change, the complex socio-political arena in which mHealth

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<sup>139</sup> For example, in 2008 and 2009, Uganda alone had 23 mHealth initiatives that did not scale up following the pilot phase; in 2009 there were more than 30 in India that went no further than piloting (Lemaire 2011, 12).

programmes are designed and implemented, and the context-specific approach necessary to achieve effective health and development communication (as discussed in the previous two chapters), these models of evaluation—and the ‘best practices’ they beget—may not always be appropriate.<sup>140</sup> Thus, while ‘hard’ evidence is no doubt important to guide innovation and investment and help policymakers set priorities in the allocation of both financial and human resources for mHealth intervention, we must not disregard alternative, more qualitative methods of evaluation, nor descriptive reflections on implementation experiences, at least while the field is still in its relative infancy. If we demand evaluations that are too rigid and quantitative, too early, we risk undervaluing the results and lessons from interventions that are still in an experimental phase and do not yet conform to established parameters (Sherry and Ratzan 2012, 2).

Insight from these early experiences is critical, in that it “will help channel investments in more productive ways even while it sheds a cautionary light on emerging mHealth myths,” such as the pervasive myths that mHealth communication interventions are simple to design and operate, universally applicable, inexpensive, wide-reaching, and demonstrably cost-effective (Sherry and Ratzan 2012, 1). Early insights are crucial in helping us advance our understanding of the dynamics of developing and implementing mHealth programs, in terms of what efficiencies can be gained, what strategies are effective, what models are scalable, what cost-savings can be expected, and what outcomes can be achieved. Even though there is no all-encompassing model that will be universally applicable, such deepened understanding will help identify the critical issues and challenges that need to be addressed in bringing mHealth programmes from pilot to scale to help bridge the resource

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<sup>140</sup> Moreover, the nature of mHealth communication intervention, as with health communication in general, means that health impacts of these initiatives are actually quite difficult to measure, given the interactions of multiple influences on health attitudes and behaviour, and the inability to decisively identify the reasons for any changes. In other words, the technical capacity of mobile telephony may make it easy to monitor how many people are accessing a service, but it is more challenging to ascertain broader health impacts.

gaps in developing country health sectors. Hence, as I narrow my focus now to explore the range of concrete mHealth applications that have been developed and deployed to support different areas of HIV and AIDS intervention in development contexts (especially in sub-Saharan Africa), I will consider anecdotal evidence and qualitative observations, alongside other measurements and results, for the valuable insights they offer into the opportunities and challenges in using mobile phones in this context.

#### **4.2 mHealth for HIV/AIDS in Developing Nations: Opportunities and Successes**

Health systems in developing countries are confronted by a number of challenges: the high burden of disease (including high prevalence of infectious diseases like HIV, TB, and malaria), weak health systems infrastructure, and health worker shortages that mean inadequate human resources capacity to cope with this burden. In this environment, the use of mobile phones presents a number of unique opportunities to mitigate some of these challenges, stretching limited resources to extend the reach of health information and service provision, and improving the quality of care through enhanced connections between citizens, health care workers, health information networks, and public health organizations. These opportunities can be broadly divided into two general groups: applications that are designed to be implemented within the health sector directly, creating organizational efficiencies, improving data flows, and supporting health workers in their jobs; and applications that directly target the general public, engaging them in health-related activities, improving access to quality health information, linking them with health services, and encouraging preventive or health-seeking behaviours (Mechael 2009, 109-110). Both of these approaches to mHealth intervention are perceived to have significant potential to improve the accessibility and quality of care for citizens living in developing countries, including specifically supporting and advancing health systems and interventions in the field of

HIV/AIDS (Feder 2010; Kahn et al. 2010; Leach-Lemens 2009; Vital Wave 2009).

Within these two broad application groups, mHealth projects have been initiated that target a diverse range of objectives, addressing many different facets of the HIV continuum, from prevention and awareness outreach, through to care and treatment support. More practically, we can identify four categories of mHealth applications:<sup>141</sup> (1) enabling data collection and disease surveillance; (2) supporting frontline health workers; (3) enhancing treatment and care; and (4) connecting citizens with health information and services.

Appendix B provides a brief description of each of the first three categories vis-à-vis HIV and sub-Saharan African contexts, along with select examples of successful projects. These many and often more technical implementations of mHealth intervention are no doubt important, presenting direct and specific opportunities to strengthen health systems in developing countries through increased efficiencies, reduced geographic barriers, and enhanced access to information, training, and ongoing support for health workers and their patients. However, from a media studies perspective I am most interested in the fourth area of focus, in which mobile phones are employed as instruments to support health communication aimed at the general population. I will therefore describe these specifically communication-based approaches to using mobile phones in HIV/AIDS and other health interventions, here.

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<sup>141</sup> For clarity and simplicity, I have chosen to use only these four general categories here. However, this range of mHealth applications can be classified in a number of different ways, and different typologies have variously been adopted by different researchers and organizations. For example, some have elected to use the categories of “education and awareness, remote data collection, remote monitoring, communication and training for health care workers, disease and epidemic outbreak tracking, diagnostic and treatment support,” (Vital Wave 2009, 9), while Mechaël et al. classified interventions under the themes of “treatment compliance, data collection and disease surveillance, health information systems and point-of-care support, health promotion and disease prevention, and emergency medical response” (2010, 10). Meanwhile, Free et al. identified 13 different categories of intervention, aimed either at health researchers, health care professionals, patients, or the general population (2010, 4). These varying typologies reflect the fact that the precise nature of various mHealth applications is difficult to classify, because of the diverse aims and approaches taken by different organizations, the overlapping areas of focus amongst applications, and the lack of conceptual clarities and consensus on a common terminology. This is emblematic of the wider landscape of the field of mHealth in developing countries, with its scattering of pilot projects and research, as discussed above.

#### 4.2.1 *Connecting Citizens with Health Information and Services*

Communication-oriented applications strategically employ mobile phones as instruments to strengthen information and communication-centric responses to the epidemic, in what we can call ‘mHealth communication’ (see also de Tolly and Benjamin 2012). These applications recognize that mobile phones are a compelling tool for health communication in development contexts, creating new low-cost opportunities for accessible, engaging mass education and outreach as a result of their capacity to reach people in remote areas and those without access to other communication channels (Déglise et al. 2012; Gurman et al. 2012). In this sense, mobile phones are the latest “mass medium” for health and behaviour change communication (de Tolly and Alexander 2009, 1). As discussed above, the personal, private, unobtrusive nature of the technology, and its potential to provide anonymity, is also particularly effective for communicating about confidential or stigmatized health issues (Mechael et al. 2010, 36). A broad range of mHealth communication applications have been piloted that serve to connect citizens and communities with both health information and health services. This encompasses interventions such as disease prevention, health promotion, education, awareness, counselling, and other outreach activities. Clearly, this type of mHealth application has many implications for HIV/AIDS communication, both for the facilitation of HIV prevention and outreach, and for persuading and enabling people to access essential services like HIV counselling and testing (HCT).<sup>142</sup>

There are several established and commonly cited examples of this kind of mHealth

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<sup>142</sup> HCT encompasses both the kind of testing I am referring to here—usually referred to as voluntary counselling and testing (VCT) or client-initiated testing and counselling (CITC)—and provider-initiated testing and counselling (PITC), in which HIV testing is initiated and recommended by the health provider in contexts such as antenatal care, TB services, or STI clinics (South Africa Department of Health 2010; UNAIDS 2004). Regardless of the testing type or environment, HCT conduct should always adhere to the “three C’s”: it should be confidential, accompanied by counselling, and conducted only with informed consent (UNAIDS 2004, 1).

communication in the West.<sup>143</sup> However, there are an increasing number of recent African-based initiatives of this nature that are more instructive as to the dynamics involved in employing mobile phones for mass HIV education and outreach. One prominent example is the work of the Dutch non-profit organization Text to Change, which has partnered with the AIDS Information Centre (AIC) in Uganda to build upon existing campaigns and services to increase local citizens' HIV and AIDS awareness and knowledge, and to motivate people to seek HIV testing. In its initial pilot in 2008, the program sent a series of SMS-based multiple choice quizzes to 15,000 subscribers of Zain (one of three mobile providers in the area, formerly called Celtel) in the rural Mbarara region, over a period of eight weeks (Mechael et al. 2010, 42; Mitchell et al. 2011). If participants answered the questions correctly, the system sent them additional information about the topic; if they answered incorrectly, they received the correct answer and an explanation. This interactive model of HIV education aims to increase (and measure) basic knowledge of HIV transmission and prevention, and to encourage uptake of VCT services, reinforced by a final reminder at the end of the quiz period to seek free VCT at a local clinic (Déglise et al. 2012, 6; Hoefman and Apunyun 2011). Participation was incentivized with prizes such as free airtime and mobile phones (Chib et al. 2012).

In 2009, Text to Change repeated the project in the Aura district in Uganda, sending the quiz to 10,000 subscribers of the mobile service provider MTN (Chib et al. 2012). Text to Change has since expanded their work to numerous other districts throughout Uganda and to other African countries, including Kenya, Namibia, and Tanzania, and this mass messaging

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<sup>143</sup> For example, one of the earliest such interventions, in the area of sexual health, is the SexInfo program in San Francisco. SexInfo was launched in 2006 in response to rising rates of gonorrhea in the area, especially amongst heterosexual African-American youth (Levine et al. 2008). It is a text messaging service offering basic information on sexual health and relationships, providing referrals to clinical and social services, and promoting safer sex practices. After seeing advertisements for the program on bus shelters, posters, handouts, or online, users could text the word "sexinfo" to an advertised number to get a directory of codes linking to information of interest, such as "what 2 do if ur condom broke," "2 find out about STDs," or "if u think ur pregnant" (the top three inquiries) (Levine et al. 2008, 394).



outreach has been complemented by workplace-based text message interventions (texttochange.org). Although the results have been positive, generating significant increases in the number of people requesting HIV tests at clinics in targeted areas (Hoefman and Apunyun 2011; Mitchell et al. 2011; Vital Wave 2009, 25-26), Chib et al. (2012) caution against over-enthusiastic interpretation of these results as outright evidence of the positive effects of SMS-based programs on HIV knowledge and testing. The response rates were relatively low, the significant majority of participants were male, and the quizzes were only offered in Uganda's official language (English) although there are 43 living languages in the country and most citizens speak a primary language other than English<sup>144</sup> (Chib et al. 2012; Déglise et al. 2012, 15; Hoefman and Apunyun 2011; Mitchell et al. 2011, 774). Moreover, Chib et al. (2012) found that the project had relatively limited success in increasing HIV/AIDS knowledge on a large scale, and that participants who already knew the correct answers were more likely to respond. This could potentially reinforce entrenched knowledge divides within the population, especially since the project design did not include sending any educational information to those who declined to participate in the quiz.

Another African initiative designed to address similar awareness-raising and testing objectives is Project Masiluleke, launched in South Africa in 2008. It involves North-South collaboration between a number of private and non-profit organizations including PopTech, iTech, The Praekelt Foundation, LifeLine Southern Africa, Frog Design, and MTN, among others (PopTech 2010). Widespread HIV testing is crucially important to both prevention and treatment strategies, yet stigma and other socio-structural barriers inhibit people's desire to access the HCT services that are widely available. This is particularly critical in a nation like South Africa, where nearly one in five adults is infected (UNAIDS 2009), yet very few know

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<sup>144</sup> Text to Change also discovered that it was essential to market the service through extensive promotion on radio, billboards, newspapers, and to include an introductory message explaining the program and guaranteeing anonymity, so as to help potential recipients feel comfortable participating in the quizzes (Michael et al. 2010, 42).

their status, and many wait until the late stages of infection to seek testing and treatment, with critical implications for both their own health outcomes and the ongoing risks of unknowing transmission (Peltzer et al. 2009).<sup>145</sup> Recognizing the critical imperative of increased HIV testing, Project Masiluleke<sup>146</sup> aims to encourage citizens to seek VCT, while also promoting awareness and education to combat social stigma that inhibits health-seeking behaviour.

The core component of the project is structured around the use of mass HIV/AIDS awareness-raising and educational messages that are inserted into the unused space at the bottom of “Please Call Me” (PCM) messages.<sup>147</sup> Mobile provider MTN donates 5% of this space for use by Project Masiluleke, and one million of these tagged PCMs are sent every day to South African mobile subscribers (PopTech 2010; Rosenthal 2011). These messages are crafted by local partners to be culturally appropriate, are sent in seven of South Africa’s most widely spoken languages, and address a number of different topics<sup>148</sup> relating to HIV and AIDS. The messages motivate recipients to pursue further information and VCT, directing them to the existing government-funded National AIDS Helpline, where operators have been trained to respond to specific messages (and provided with an accompanying

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<sup>145</sup> This study suggests 7.8% knew their HIV status in the past 12 months, although less conservative estimates suggest this figure is higher. For example, PopTech states that less than 25% of South Africans have been tested for HIV (PopTech 2010). However, this number has likely increased significantly in the past two years, since the South African government launched an immense national HCT campaign in April 2010, which aimed to see 15 million South Africans tested by June 2011 (Bodibe 2011). Although the country remained 5 million under target after 15 months (Bodibe 2011), the 2010 testing rate had improved 500% over the year before (Mail & Guardian 2010).

<sup>146</sup> Masiluleke means “give wise counsel” or “lend a helping hand” in Zulu (PopTech 2010). Zulu is one of the most widely-spoken languages in South Africa, and the dominant language in KwaZulu-Natal, the province in which the project is based (although it has a national reach). KwaZulu-Natal also bears the highest rates of HIV prevalence in the country (Gouws and Karim 2005).

<sup>147</sup> As mentioned in Chapter Two, PCMs are a special form of SMS that are free to send, allowing users to ask the recipient to call them back if they are out of airtime, or they do not want to use their credit to make a call. These messages have 120 characters of unused space at the bottom of the message that can be used for advertising or social messages. PCMs are a widely used method of communication across the African continent: more than 30 million PCMs are sent every day in South Africa alone (Rosenthal 2011).

<sup>148</sup> The message themes include prevention, testing, treatment, stigma, discrimination, symptoms, disclosure, PMTCT, TB, traditional medicine, immune boosters, ARVs, children and HIV, and pro-acceptance. Translated examples of these messages include: “HIV + man or woman & want to have a healthy HIV negative baby? For advice please call AIDS Helpline 0800012322”; “Are you losing weight and scared you might be HIV positive? Call AIDS Helpline 0800012322 and get tested today”; “HIV positive and scared to tell your partner? For info on how to disclose your HIV status, call AIDS Helpline on 0800012322” (National AIDS Helpline 2011).

script and answers to frequently asked questions on the topic), and given the software tools to track responses by message theme, age, gender, and province so as to test the effectiveness of various message themes, content, and languages with different groups<sup>149</sup> (PopTech 2010; Rosenthal 2011). In the first two years of the project (October 2008 – October 2010), Project Masiluleke sent over 968 million tagged PCM messages, and has helped to triple the number of average calls to the helpline<sup>150</sup> (National AIDS Helpline 2011; PopTech 2010).

Seeking to expand its impact, Project Masiluleke is in the process of developing a low-cost HIV self-testing kit (analogous to a home pregnancy test) supported by counseling via mobile phones, and is also using the Praekelt Foundation's TxtAlert service (discussed in Appendix B) to keep ART and TB patients connected to care (PopTech 2010; Rosenthal 2011). Through these various components, Project Masiluleke has significant potential to support an integrated patient-centred model for mHealth communication and care vis-à-vis HIV/AIDS, from outreach and awareness through to HIV testing and treatment follow-up. However, the project is potentially limited by a lack of full-time staff, an unsustainable financial model (it is dependent on donated time and resources from project partners, as well as various philanthropic grants), and its reliance on existing strained health infrastructure and services (Rawlings 2011). For example, only 60% of calls driven to the National AIDS Helpline were answered, because of insufficient staff capacity (National AIDS Helpline 2011). Moreover, calls to the helpline are only free from landlines, which are inaccessible to

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<sup>149</sup> Helplines were developed early in the epidemic as important communication platforms offering advice, feedback, and information in a private, anonymous, sensitive, and non-biased manner, and have long been an important part of the AIDS response in many African countries, including Ghana, Uganda, Nigeria, Mozambique, Kenya, and Zambia (Fuller 2008, 171). Some initiatives have recently integrated these telephone services with mobile systems. For example, La Ligne Verte (French for "hotline") was established in the Democratic Republic of Congo as a toll-free mobile phone hotline for confidential family planning information and clinic referrals—particularly beneficial in a country where access to health information and services has been compromised by violence (Corker 2010; Mechaël et al. 2010, 39). In Ghana, a program called Text Me! Flash Me! was established as a health promotion and counselling service helpline aimed at MSM and female sex workers (Déglise et al. 2012; Gurman et al. 2012).

<sup>150</sup> The project tested its impact on driving calls to the helpline by running a five week-long pilot of a USSD (text menu) quiz without advertising the Helpline number, and experienced a substantial drop in calls. Call volumes increased again once the tagged PCM messages resumed (National AIDS Helpline 2011).

many South Africans, particularly in rural areas, and citizens may be unwilling to bear the cost of a call from their mobile phones (Rawlings 2011, 8).

#### *4.2.2 mHealth Communication in the Context of Behaviour Change Theory*

Most of these mHealth communication interventions can be understood as consistent with the behaviour change communication discussed in Chapter Three—harnessing the reach and utility of mobile phones with the explicit intention of changing citizens’ behaviour—and as such have been referred to as mHealth BCC, or mBCC (see, for example, Gurman et al. 2012; Umapathy et al. 2012). Indeed, mobile technology has the potential to facilitate more appropriate, interactive, and effective behaviour change communication throughout the entire range of mHealth application categories described in this chapter. Two recent handbooks have been produced by practitioners in the field of mHealth, acknowledging this potential for mHealth applications to address behavior-related health challenges, and offering guidance on the most effective strategies, approaches, and research activities to engage mobile communication for behaviour change interventions (Frontline SMS/Text to Change 2012; Umapathy et al. 2012). These guides acknowledge that mobile phones might not always be the most appropriate communication tool available, and offer a number of steps and modes of analysis that should be conducted during the application development process. These resources are important, because to date most mHealth applications have failed to adequately integrate or report any theoretical basis for their projects, despite evidence that theory-driven BCC interventions are most effective (Cole-Lewis and Kershaw 2010; Riley et al. 2011). As Mechael et al. note, for the most part “the field of mHealth has yet to embrace the behaviour theory to underpin its projects” (2010, 29). There may be evidence of projects that have ‘worked’ in some respect, but without a theoretical understanding of which elements led to success in different contexts, it will be difficult to expand and scale mHealth applications. As

with eHealth interventions more generally, greater application of behaviour and communication theories might help to address existing gaps in mHealth research and implementation, and deepen our understanding of what elements are critical for effective interventions<sup>151</sup> (Mechael et al. 2010, 29; Pingree et al. 2010).

This failure of mHealth practitioners to adequately consider or test the applicability of these health behaviour theories to mobile interventions (Evans et al. 2012; Riley et al. 2011) can perhaps be interpreted as part of the more general ahistorical outlook that characterizes much of mainstream ICT4D theory and practice. This outlook neglects to situate mHealth as a part of the long history of health and development communication initiatives, and therefore does not take into consideration the lessons and legacies of these earlier interventions. For example, despite the calls for an Interactive Health Communication facilitated by ICTs, as discussed above, most mHealth interventions have not fully embraced and exploited the interactivity and feedback potential of mobile phones. SMS has been the most common technology used in these mHealth applications, implemented primarily as a one-way broadcast technology, which means that the interactive potential afforded by mobile phones is not being fully leveraged<sup>152</sup> (de Tolly and Benjamin 2012, 326; Déglise et al. 2012; Gurman et al. 2012; Mechael et al. 2010, 43; Riley et al. 2011). Although the development of mHealth communication interventions—for HIV and AIDS, as for other health issues—is perhaps still in its nascent stage, it will be important for those involved in designing these applications to harness the interactive potential of mobile as much as possible. Such interactivity may be essential in helping to realize mHealth’s transformative potential in

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<sup>151</sup> However, Riley et al. (2011) note that current health behaviour theories may be somewhat inadequate for the dynamic, interactive, and adaptive communication potential of mobile telephony, and thus these theories need to be evaluated, adapted, and advanced to better inform mHealth intervention development.

<sup>152</sup> de Tolly and Benjamin suggest that this is partly due to economic reasons—as interactivity of mHealth applications increases, costs tend to escalate accordingly (2012, 326). I will explore some innovative and less expensive interactive solutions that have been piloted by Cell-Life, in the following chapter.

health communication, as they pursue more dialogical, participatory, context-specific, and communication-based modes of intervention—rather than one-way information dissemination.

In order to further explore the dynamics involved in developing mHealth Communication applications, and to illustrate the potential for this kind of interactivity, the next chapter presents a practical case study, Cell-Life, and discusses the opportunities and challenges they have encountered in deploying mHealth for HIV/AIDS in South Africa.

**--- CHAPTER FIVE ---**  
**EXPERIENCES FROM SOUTH AFRICA:**  
**CHALLENGES AND COMPLEXITIES IN MHEALTH IMPLEMENTATION**

The previous chapter has presented a survey of the field of mHealth and an analysis of the range of opportunities afforded by the application of mobile phones to support and advance HIV/AIDS intervention in sub-Saharan Africa. This chapter seeks to further contextualize this analysis through a practical case study situated in perhaps the world's most compelling environment for HIV-related mHealth initiatives: South Africa. To exemplify the possibilities for mHealth discussed above—particularly for communication-oriented interventions, as opposed to more technical solutions—and to further examine actual experiences in implementation of real-life mobile phone-based communication projects addressing HIV and AIDS, this chapter presents a case study of Cell-Life, a South African non-profit organization that has been a pioneer in the field of mHealth in Africa.

I will begin by briefly articulating why the South African context presents such an instructive environment for analysis of mHealth interventions responding to AIDS, before introducing Cell-Life and its long history in mHealth in South Africa. I will describe the organization's diverse range of projects and innovations that address the full range of interventions in the AIDS continuum, highlighting in particular some of its particularly promising work built around more interactive mHealth communication approaches. I will then discuss the range of constraints and critical issues inherent in developing and implementing HIV/AIDS-oriented mHealth applications, as revealed by analysis of Cell-Life's experiences over the past decade. Through discussion of these challenges and complexities as experienced by Cell-Life in their mHealth work, alongside other issues that have been identified in academic literature and mainstream policy discourse on the subject, I

will highlight the primary barriers to sustainable and scalable implementation that persist for HIV/AIDS-oriented mHealth communication intervention in sub-Saharan Africa. This discussion will highlight the limitations that may inhibit the full realization of mHealth's promise in this context, including the critical issues of funding, technical constraints, interoperability, privacy, language and literacy, access divides, participation of end-users, and partnerships with government and the private sector.

### **5.1 Case Study: mHealth in the South African Context**

As I have argued in this thesis, sub-Saharan Africa presents an environment where mHealth has the potential to make perhaps the most significant impact on health systems—especially vis-à-vis AIDS—given the enormity of the health challenges faced and the increasing ubiquity and significance of mobile phones. Within this region, though, South Africa in particular offers a uniquely compelling environment within which to examine the dynamics of developing and implementing HIV/AIDS mHealth applications. South Africa has both an acute need for such innovations in order to extend the reach of limited resources to cope with the country's immense HIV burden, and simultaneously an almost universal adoption rate of mobile telephony—a perfect opportunity for HIV/AIDS mHealth intervention. In addition, South Africa is characterized by extraordinary linguistic, geographic, and cultural diversity—exemplified by its eleven official languages—and hence mHealth applications developed here might meaningfully be adapted for other contexts of diversity. Hence, South African mHealth applications are particularly worthy of examination, potentially providing valuable guidance in the development, deployment, and optimization of applications in other African settings, especially as mobile penetration continues to increase across the continent.

South Africa bears the weight of one of the world's most severe HIV epidemics: with



an overall adult prevalence at 17.8%<sup>153</sup> and over 1,000 people newly infected daily, it is home to nearly six million HIV positive people—the largest number in any country worldwide (South Africa 2012; UNAIDS 2010c). It is arguably one of the best-equipped African countries to deal with such an enormous health challenge, yet the high cost of ARV drugs, compounded by the government's delayed, ineffective, and devastatingly counterproductive initial response,<sup>154</sup> meant that the epidemic in South Africa quickly escalated into a public health crisis of such a monumental scale that even the best political leadership with plentiful financial, human, and material resources would struggle to mount an effective response.<sup>155</sup> Recently, South Africa's government has shown significant leadership on AIDS, enacting progressive policies (such as the HCT campaign noted in Chapter Four) and scaling-up its treatment programs to be the world's largest.<sup>156</sup> Yet the epidemic remains a serious public health challenge for the country, and efforts to achieve universal access to prevention and treatment continue to be logistically formidable, not to mention a burden on human and financial resources. In fact, securing the financial, infrastructure, and human capacities for strengthening the overburdened health system in order to meet the immense scale of the demand for services is particularly challenging in the current international political and economic landscape, in light of the global economic recession and the

<sup>153</sup> This figure refers to adults aged 15–49 years of age, the standard UNAIDS prevalence measure. The prevalence amongst pregnant women attending antenatal clinics was 30% in 2010, although in some provinces it is much higher—for example, there was a 39.5% prevalence in KwaZulu-Natal (South Africa 2012, 31, 34).

<sup>154</sup> While the HIV epidemic began to intensify in South Africa, the country was distracted by its political transformation from apartheid to democracy—AIDS was simply not on the political radar—and this inattention soon gave way to outright stonewalling and denial of AIDS science, as leaders like President Thabo Mbeki and Health Minister Tshabalala-Msimang rejected the safety and efficacy of antiretroviral drugs (see Robins 2004; Thornton 2008). South Africa's response to the epidemic was indisputably hindered by the government's protracted period of AIDS denialism and chronic inaction. The controversies, conflicts, and implications of this period of denialism are far too complex to discuss here; see Nattrass (2007) for a comprehensive chronicle of this period. She has demonstrated that it was clearly this lack of political will, rather than economic, infrastructure, or human capacity limitations that crippled South Africa's response to the epidemic, as many poorer countries with greater infrastructural challenges—yet stronger political commitments to tackle AIDS—have performed better in providing citizens access to ART (Nattrass 2007, 5–8).

<sup>155</sup> As a result of fierce activism of groups like TAC, HAART rollout began in the country in 2004 (Nattrass 2007). By 2009, domestic AIDS spending in South Africa surpassed R15 billion (US \$1.8 billion), not to mention international spending from donors like PEPFAR (South Africa 2012, 29).

<sup>156</sup> South Africa's Department of Health reported that by 2011, 1.8 million people had initiated HIV treatment, representing 75% of those eligible for ART, and that the country had achieved 87% coverage for PMTCT programs (South Africa 2012, 28).

corresponding decline in global AIDS funding. Thus, it remains crucial for South Africa to exploit the tools on hand and develop initiatives that will extend the reach of its limited resources, maximizing their impact in the ongoing response to AIDS.

At the same time, the communications landscape in South Africa is characterized by a remarkable ubiquity of mobile phones—the country is a leader in sub-Saharan Africa in this respect. By 2010, there were more active mobile subscriptions than there were citizens in South Africa (ITU 2011b). Even accounting for multiple ownership (some people having more than one phone), an estimated 90% of all youth and adults use mobile phones (Benjamin 2010). In South Africa, there is no cost to users to receive mobile voice calls or text messages, and with innovations like the PCM messages discussed above, this technology affords new opportunities to communicate with even the poorest communities, and those in deep rural areas—important in a country of both sprawling urban townships and remote villages. Given the extraordinarily broad reach of mobile telephony relative to other communication technologies—together with the political and historical factors that contributed to health challenges such as the pervasive HIV and TB epidemics—it is no surprise that South Africa has been on the forefront of mHealth experimentation. Numerous pilots and programs have been launched by both local and international organizations. One such organization particularly worthy of closer examination is Cell-Life, a non-profit enterprise based in Cape Town which has been one of the earliest, most innovative, and most prolific leaders in the field.

I first encountered Cell-Life in 2008 and have followed their activities and evolution over the ensuing years with considerable interest. I have been impressed at the scope and quality of their work, and the ways in which they have seized opportunities and adapted technologies with sensitivity to South Africa's particular needs, challenges and constraints.

Cell-Life's extensive activities thus present a special opportunity to exemplify the possibilities for mHealth and HIV/AIDS communication in the South African context. I interviewed Katherine de Tolly, Cell-Life's mHealth Project Manager and Senior Researcher in 2012 to obtain her perspectives and explore Cell-Life's successes and challenges as they pertain to this thesis. Drawing upon that interview, as well as Cell-Life's own documentation and a limited number of external publications, I will describe here how Cell-Life has seized the above-mentioned opportunities presented by mobile telephony vis-à-vis health and development intervention—opportunities that are particularly cogent in South Africa. In so doing, I will identify insights garnered from their real-life experience in implementing such projects. I will first present an overview of Cell-Life and the projects they have initiated. Then, in the next section below, I will outline some of the challenges and complexities they have experienced in developing and implementing these applications, alongside other issues that have been highlighted in both academic and gray literature.

#### *5.1.1 Cell-Life: Pioneering mHealth in South Africa*

Recognizing both the need for innovative solutions and the opportunity presented by new ICTs to strengthen the nation's health systems and AIDS epidemic response, Cell-Life has been creating applications of appropriate technology (primarily mobile phones) for the HIV and health sectors in a developing-country context for more than a decade. Since its inception, Cell-Life has demonstrated leadership in the field of mHealth—their work, of course, pre-dating the popularization of the term—deploying open-source software geared toward each of the four application categories identified in Chapter Four, and piloting projects that address the entire HIV continuum, from prevention, education and outreach to treatment and care support. The organization has fostered collaboration in the field, and is working in partnership with over 100 other public, private, and non-profit health and

HIV/AIDS organizations (Benjamin 2010).

Cell-Life was born as a research project in the Faculty of Engineering at the University of Cape Town in 2001, conceived to support HIV care and the rollout of ART (Cell-Life 2009). The project was developed in partnership with the Cape Peninsula University of Technology, where Cell-Life is now based, and in 2005 it became its own non-profit organization.<sup>157</sup> The original project created a system called “Aftercare” that linked CHWs treating people living with HIV in Gugulethu (a township of Cape Town) with doctors and nurses at a central clinic. The Aftercare system enabled carers to use mobile phones for data collection to support and monitor HAART patients’ adherence to their treatment regimens, as well as to keep track of other general information about their health status and care.<sup>158</sup> While technologically sophisticated, the software was designed to be simple to use, and to be operated on a low-cost phone. By improving communication between carers and health centres and reducing the administrative burden of data capture and analysis, the system improved the efficiency and quality of care, and helped the CHWs to feel more secure, effective, and empowered in their roles, enhancing their status in the community (Skinner et al. 2007; Wessels et al. 2007).

Cell-Life has continued to develop this system, which has evolved into a mobile data collection platform now known as “Capture,” used for a wide range of data capture, monitoring, and reporting activities, from condom distribution to treatment literacy and training sessions (Cell-Life 2012). One particularly notable use of the Capture platform

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<sup>157</sup> To enhance the organization’s financial sustainability, Cell-Life has also developed its own commercial subsidiary (called mHealth Solutions), which will sell Cell-Life’s products and services to the commercial health industry, generating revenue to support Cell-Life’s work as a non-profit organization (Cell-Life 2009). Apart from this solution, Cell-Life operates on grant funding from The Vodacom Foundation, The RAITH Foundation, Johns Hopkins Health and Education South Africa, USAID, PAPFAR, and Right to Care, as well as other supporting partners for various projects (Cell-Life 2009; de Tolly 2012).

<sup>158</sup> This mobile phone-based monitoring system allowed these frontline health workers to enter data onto their phones during home visits in the community, and this information was sent via SMS to a secure central database accessible by the clinic staff (for more detailed studies, see Skinner et al. 2007; Wessels et al. 2007).

involves a national rollout of the system to health facilities nationwide. In 2010, South Africa's national Department of Health contracted Cell-Life to design and implement a Mobile Monitoring and Reporting system for its HCT campaign and expanded ART program, and is distributing 15,000 'feature phones'<sup>159</sup> to health workers nationally to collect data about these campaigns and improve upon paper-based reporting systems (Benjamin 2010; Cell-Life 2012, 14). Although the program is still currently in the training phase (de Tolly 2012), the large scale of implementation—involving all health facilities in the country—is significant, indicative of the government's interest in embracing mHealth systems as well as Cell-Life's recognized leadership in the field. Another health sector-oriented application that Cell-Life has developed is iDART—the “intelligent Dispensing of Antiretroviral Treatment”—a software system designed to support HAART rollout by allowing pharmacists and clinicians to accurately and efficiently monitor and manage ARV drug dispensing and supplies through the use of bar code labelling and scanning (Cell-Life 2012). iDART is a free, open-source software solution that has been implemented in over 100 ART dispensing sites in South Africa (and a further 250 down-referral sites), supporting ART distribution to over 300,000 patients (Cell-Life 2012, 6). It is also currently being piloted in Nigeria.

In addition to these more technical applications aimed at increasing efficiency and efficacy of the health sector, a third focus of Cell-Life's innovation is the “Communicate” platform, which is of particular relevance to health communication for development, and thus most pertinent to this thesis. Communicate was launched in 2007 as the “Cellphones 4 HIV” project (also previously known as “Mobilisr”) to explore the range of potential applications of mobile phones for information, communication, and interactive services in support of both

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<sup>159</sup> 'Feature phones' refers to a broad range of mobile phone models that are usually Java enabled so they can run games or Java applications, and can make a data connection (although they are not necessarily used to do so). In South Africa, 65% of mobile handsets are feature phones, while 25% are the most basic phones with just voice and SMS capabilities, and only 10% are high-end smartphones (de Tolly 2012). This variability in phone functionality represents a design challenge for mHealth applications, as I will discuss below.

the HIV sector and people living with HIV (Cell-Life 2009). Although some of these applications are geared toward supporting HIV organizations themselves, strengthening their organizational capacities, many of these solutions are designed to enable direct interaction with the general public, allowing for tailored education and behaviour change communication campaigns to be delivered via mobile phones, and facilitating connections to HIV information and services. The Communicate platform comprises a number of different services that harness a wide range of functionalities offered by mobile phones. Some of the specific tools and technologies that Cell-Life has adapted and applied to serve diverse mHealth communication purposes include: Broadcast SMS (sends a bulk SMS to a list of known numbers and can be scheduled as desired); Interactive SMS (people can send a keyword in an SMS to automatically receive information, subscribe or unsubscribe from a service, answer a poll, or donate money to a pledge line); USSD text menus (an interactive menu-driven service that allows users to access content on different pages); PCM messages (people can send a free PCM message as a signal, such as to subscribe to a list, find a local service, or receive information); location-based services (networks can triangulate a phone's position, and hence people can be referred to local services, such as the nearest clinic); WAP/Mobisites (websites optimized for viewing on mobile phones); MXit (instant messaging chat application and information portal); and Cell Books (a book created to be downloaded via WAP to a mobile phone) (Cell-Life 2009, 2012; de Tolly and Benjamin 2012). Given the low penetration of high-end smartphones and the great variability in handset functionality amongst mobile phones in use in South Africa, Cell-Life ensures that most of their Communicate applications and services work on all phone types,<sup>160</sup> including the most basic handsets (Cell-Life 2012, 7). In addition, they have strived to, where possible,

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<sup>160</sup> Although some of the more advanced technologies may require at least a feature phone with a data connection, and the organizations creating and communicating the content might need a computer to develop some interventions, most of the applications have very low technical requirements for the end-user in the general public.

design services that bear no cost for the user, or (as with services like Mxit) have such a minimal cost that they are accessible to all but the very poorest populations (de Tolly 2012).

This domain of Cell-Life's work is based on an understanding of the central role of communication in HIV intervention. Indeed, as I have argued in Chapter Three, communication is essential not only for basic information and education—which no doubt remains vitally important in South Africa<sup>161</sup>—but also for changing attitudes about HIV and AIDS, mitigating the negative effects of social stigma and discrimination, facilitating peer support and counselling, promoting the uptake of important HIV services like VCT and PMTCT, and supporting HIV positive people with treatment literacy and adherence reminders. In this context, Cell-Life's suite of innovations, systems, and services apply the tools and technologies mentioned above to communication interventions addressing the full AIDS continuum.

Moreover, Cell-Life is deploying solutions and conducting formal research studies that contribute to the mHealth communication evidence base. Many of these projects have used the broad reach and cost-effective nature of SMS communication. For example, an early pilot project sought to support ART adherence by sending twice-daily SMS reminders in English or Xhosa to members of “adherence clubs” run by TAC and the Department of Health, along with treatment literacy information<sup>162</sup> (de Tolly and Alexander 2009). More recently, Cell-Life completed a research study investigating the effectiveness of SMS messages to expand the uptake of VCT, and the impact of motivational versus strictly informational messages at various frequencies (either 3 or 10 SMS messages over the

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<sup>161</sup> The ongoing need for accurate information about HIV remains especially critical amongst young South Africans. In the last national research survey conducted in the country, only 28.7% of young men and women aged 15-24 could correctly identify the ways of preventing sexual transmission of HIV and reject major misconceptions about HIV. The percentage was slightly lower for women than for men (Shisana et al. 2009).

<sup>162</sup> Sample messages include: “It’s ARV time! Hope you’re feeling well today but remember to keep eating even if you feel sick. Your immune system needs energy to fight off infections,” and “Remember your pills. DdC, d4T, ddl and 3TC can cause tingling in your hands and feet. If untreated this can become very painful. Speak to your doctor” (de Tolly and Alexander 2009, 10).

duration of the study)<sup>163</sup> (de Tolly et al. 2012). Another study is being implemented to evaluate the impact of SMS messages supporting HIV-positive mothers enrolled in a PMTCT program for 10 weeks after birth, to help improve follow up and HIV testing rates of their infants<sup>164</sup> (de Tolly et al. 2010). To facilitate more widespread use and leverage of its innovations, Cell-Life also offers several pre-set message campaigns that can be tailored to specific implementation contexts, including programs for adherence, PMTCT, and people newly diagnosed with HIV (Cell-Life 2012). Cell-Life's deep and intimate knowledge of the local context is a key asset here, as these messages have been carefully crafted through a process of formative research involving close consultation with local people that work in the field, focus groups, and an increasing integration of behaviour change theories (de Tolly 2012).

To support mass outreach for HIV prevention and education, Cell-Life has developed programs for content delivery based on both USSD and MXit platforms. For example, Cell-Life has partnered with the popular entertainment-education program Soul City (discussed in Chapter Three) to extend Soul City's reach beyond its traditional mass media channels (radio and television), linking its broadcast programming to further interaction via mobile phones<sup>165</sup> (de Tolly and Alexander 2009). To experiment with the provision of HIV-related content via MXit, Cell-Life created a service called "Red" in August 2009, which provides basic HIV information relating to transmission, prevention, testing, and living with HIV (de Tolly and

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<sup>163</sup> The study recruited participants from a database of mobile phone numbers collected from mobile-based competitions advertised on the Soul City radio and television programs, and concluded that the 10 motivational messages had a statistically significant impact in terms of influencing people to take an HIV test. This study is notable not only for demonstrating that SMS campaigns can have a positive influence on the uptake of VCT, but also for its innovative design—all participant contact throughout the RCT (including recruitment and consent) was conducted via SMS (de Tolly et al. 2012).

<sup>164</sup> In 2011, Cell-Life was selected as a winner of an mHealth Alliance and UN Foundation competition and awarded funding to scale-up this SMS support program for PMTCT to 50,000 patients (Cell-Life 2012, 11).

<sup>165</sup> A pilot of this service experimented with two variations on USSD content delivery related to Soul City's "OneLove" education campaign about the risks associated with multiple concurrent sexual partners. The first service was a direct didactic information service, whereas the second version was a 'soap opera' style designed to convey the same information in an engaging narrative format. The latter option was found to be less ideally suited for the USSD format, which allows users to seek out specific information in a menu (de Tolly and Alexander 2009, 4-5).



Benjamin 2012, 322). MXit<sup>166</sup> is an especially appealing platform to connect with young people who demonstrate inadequate knowledge of HIV and yet often engage in risky sexual behaviour, in order to provide them with easy access to vital HIV information (Cell-Life 2011). In the first two years Red was available over 1.6 million pages of content were viewed, despite minimal advertising for the service, demonstrating both the desire for such cheap and accessible content and the promise for MXit-related HIV communication to be explored further (Cell-Life 2011).

Cell-Life has also leveraged the popularity and affordability of the MXit platform to provide HIV counselling via instant messaging. The service, called “RedChatZone,” was developed in partnership with LifeLine (the organization that runs the National AIDS Helpline) and launched in September 2009, allowing MXit users to access totally anonymous, private, inexpensive HIV counselling from anywhere—privacy and flexibility not possible with the existing helpline service (de Tolly and Benjamin 2012, 321). Although only available during certain hours (Monday to Friday, 3-5pm), by the end of April 2011, counsellors had conducted over 26,000 conversations (Cell-Life 2011). Anecdotal evidence from the counsellors involved suggested that the application had a positive impact on their work, allowing them to have multiple conversations simultaneously and thus help more clients, and the nature of the chat application means that they can view previous conversation history with the same user, affording a degree of continuity not possible with voice calls (de Tolly and Benjamin 2012, 322). Moreover, the low cost of the service (less than US \$0.05 for a MXit conversation comparable to a four-minute voice counselling call that would cost about US \$1) is extremely appealing for potential users, and offers promise for scale-up and

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<sup>166</sup> MXit is an immensely popular instant messaging application in the South African context (although it is also used in Kenya, Lesotho, Namibia, Nigeria, and Swaziland). There are nearly 45 million registered users in South Africa (10 million of which are active in an average 12 week period), the majority of whom are between the ages of 18 and 25 (89% are aged 35 or younger) (MXit 2012). There are 750 million messages sent daily, and 79% of users log on more than once per day, spending an average total of 87 minutes online per week (MXit 2012).

adaptation to other resource-limited contexts (Cell-Life 2011). Despite potential challenges with securing sufficient bandwidth and human resources to meet demand, this HIV communication application is particularly notable for its innovative use of the full interactivity afforded by the mobile phone—a level of dialogue not achieved through one-way mass messaging SMS campaigns.

Throughout its work, Cell-Life has consistently placed an emphasis on dialogue, interaction, and empowerment—critical elements of effective health and development communication. Some of these interventions also serve to target broader socio-structural barriers like stigma, which are crucial factors to be addressed in responding to the epidemic. Indeed, Peter Benjamin, Cell-Life’s general manager, has noted that mobile telephony also creates new opportunities to respond to the social determinants of health (like education, housing, employment, sanitation, and crime)—opportunities that, being outside the explicit domain of the health sector, are often overlooked in mHealth intervention, but should be explored alongside health promotion and disease prevention applications of mobile phones (Benjamin 2012).

## **5.2 Critical Issues, Challenges, and Limitations**

Analysis of the projects implemented by Cell-Life—as well as the many other pilots and applications I have highlighted in this thesis—no doubt reveals the significant promise and diverse range of opportunities presented by the use of mobile phones in health and development contexts, specifically vis-à-vis HIV and AIDS intervention in sub-Saharan Africa. However, this analysis also exposes a number of particular challenges, issues, and complexities that must be addressed in order to develop effective mHealth programs, as well as potential pitfalls and barriers that might inhibit sustainability and scalability—two critical factors in achieving long-term success and meaningful impact of mHealth communication

interventions in AIDS and development contexts. In part because of the anecdotal nature of project reporting to date, as discussed in Chapter Four, there has been a dearth of critical discussion and analysis of the actual implementation challenges inherent in successful deployment of these interventions. Hence, both practitioners and researchers have argued for greater dialogue and attention to these potential barriers and constraints, and have articulated the need for theories and frameworks that transform anecdotal evidence of experienced challenges into enabling and actionable information to guide future project development (mHealth Working Group 2012).

Although the dynamics involved in mHealth design and implementation vary according to specific contexts—indeed, as I have argued earlier, successful deployment of any health or development initiative depends explicitly on sensitivity and adaptation to local needs and socio-cultural contexts—we can identify at least a general framework of potential limitations of mHealth, a catalogue of critical issues that should be considered when conceptualizing and enacting projects. Such an analytical structure, informed by the rich insights and lessons from mHealth experiences to date, will naturally be a flexible, evolving framework. However, at the time of writing, analysis of the challenges and complexities experienced by Cell-Life, as well as the experiences of other mHealth organizations as outlined in academic and gray literature, suggests that some of the most pertinent perceived challenges and constraints include: technical limitations and interoperability issues; existing health infrastructure and human resources limitations; sustainable funding; the roles of government and the private sector; access barriers and divides including gender, language, and literacy; privacy and security; and participation of end users and communities.

### *5.2.1 Technical Constraints*

At the most basic level, mHealth interventions are constrained by the technological

functions of the mobile phones and networks upon which they are based. Although the technology evolves rapidly,<sup>167</sup> we can identify a number of basic technological limitations that bear upon mHealth communication initiatives. The underlying infrastructure—though not nearly as limited or expensive to deploy as some other ICTs like fixed line telephony or cable Internet—is not always universal, and patchy network coverage, service fluctuations, bandwidth limitations, and otherwise unreliable connectivity invariably constrains mHealth interventions, especially in the most rural or remote areas<sup>168</sup> (de Tolly and Benjamin 2012; Mechael et al. 2010; Sherry and Ratzan 2012). In addition, the mobile handsets themselves are susceptible to malfunction, loss, or theft, and a high turnover of mobile phones means that it may be difficult to reach people consistently (Déglise et al. 2012; Iluyemi 2009; Mechael et al. 2010; Wessels et al. 2007). In crafting health communication messages for delivery via mobile phones, different formats create limitations in terms of the length and presentation of content.<sup>169</sup> For example, SMS messages are restricted to only 160 characters: this limits the possibilities for structure and nuance of messages, and hence the communication of complex real-time information, persuasive messages, or technical material about health conditions or treatment procedures becomes a formidable challenge (de Tolly 2012; Kaplan 2006, 9; Mechael et al. 2010, 36). While USSD text menus allow users to scroll through and seek out desired information, the duration of each session is limited to about two minutes, constraining the overall volume of information that can be accessed (in addition to stability issues with frequent ‘dropping’ of sessions unpredictably) (de Tolly 2012).

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<sup>167</sup> Indeed, the rapid pace of technological advancement in the field of mobile communication, in itself, presents a challenge for mHealth project design, training, and infrastructure and technology set-up, given the difficulty of developing and deploying projects before the technological landscape has changed.

<sup>168</sup> Moreover, the lack of pre-existing eHealth infrastructure to build upon (like electronic medical record systems) in many developing countries poses a challenge for some projects, especially those linked into the health sector directly (Sherry and Ratzan 2012).

<sup>169</sup> See de Tolly and Benjamin (2012) for a good overview of the advantages and disadvantages of each of the various non-voice formats for mobile communication and interaction.

Moreover, as de Tolly (2012) noted in my interview, there is an important distinction between mHealth interventions that are based on ‘push’ and ‘pull’ technologies, each approach presenting its own unique challenges. Push technologies, like SMS, are delivered to the user directly—the message is ‘pushed’ to their phone and they receive a notification or prompt immediately—and this offers a direct, immediate, attention-grabbing channel for health communication. However, the requirement here is that organizations wishing to send SMS messages must have a list of known numbers of recipients, and thus are dependent on some sort of database.<sup>170</sup> Pull technologies, like MXit or mobisites, require the user to initiate the service, and are thus dependent on some form of advertising or publicity to promote the application. This potentially constitutes an added cost, and may not reach the entire targeted audience.<sup>171</sup>

The lack of interoperability of mHealth applications and systems presents another technical constraint that is of great concern to the mHealth community at the moment (mHealth Working Group 2012). Much of the development of mHealth technologies and services to date has been characterized by a ‘silo approach’—each intervention implemented as a single-focus solution—in part a natural result of the frenzy of pilot projects spearheaded by ‘silos’ of disease- or country-specific donor organizations (Mechael et al. 2010, 10; Schweitzer and Synowiec 2012, 75). This siloized development means that, to some extent,

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<sup>170</sup> Different organizations have taken different approaches to addressing this limitation. Cell-Life has established their own databases that collate numbers from participants in contests that they have run on behalf of organizations like Soul City and that they can use for these purposes, such as in the research study described above. They also collect numbers when users sign up to participate in a study or receive a service, such as at a clinic or some other point of care (de Tolly 2012). In Uganda, the mobile service providers allowed Text to Change to send out messages to general subscribers (Chib et al. 2012). Another solution is to use the PCM messages in partnership with the mobile provider, as Project Masiluleke has done, but the drawback is that these messages are untargeted. In our interview de Tolly (2012) also explained that the KwaZulu-Natal Department of Health does not collect the mobile numbers of patients, and hence they are limited in assessing the impact of interventions like Cell-Life’s PMTCT program, because there is no way to match up the mobile numbers receiving the SMS messages with the data collected in the clinics.

<sup>171</sup> Cell-Life has often used one communication channel to advertise a service on another. For example, they have advertised mobisites through SMS messages, and they have used the PCM channel to advertise as well (de Tolly 2012). One particularly effective mode of marketing a service, according to de Tolly, is advertising within MXit, either through ads placed on the initial loading screen, or through messages that are broadcast widely to users.

the landscape of mHealth at present can be characterized as a “patchwork of incompatible applications,” built upon differing systems, standards, and technologies (van Heerden et al. 2012, 393). Yet the possibility for mHealth to strengthen health systems at scale and achieve a broader impact than is possible with isolated pilot projects necessitates systems that are able to interoperate on common standards. In developing countries, open source software will likely need to play an important role in this. Initiatives like the Open Mobile Consortium and the Open ROSA consortium (focused on data capture, and of which Cell-Life is a founding member) have been established to help technology developers and practitioners create shared open-source solutions for social development purposes (Curioso and Mechael 2010; [openrosa.org](http://openrosa.org)). Moreover, the nature of competition and proprietary development within the mobile industry and among handset manufacturers presents a challenge. In addition to the software differences (such as Apple’s iPhone software versus Google’s Android platform), the thousands of different handsets on the market with an immense range of different features and functionalities, limits the potential reach and impact of some mHealth applications. As de Tolly (2012) explained, SMS and USSD (and voice) are the only truly ‘one-size-fits-all’ channels, and these are both relatively constrained as communication mediums, while many of the more potentially fluid and flexible channels are vulnerable to this variability of phone functionality.

### *5.2.2 Health Infrastructural Limitations*

In addition to these technology-related limitations, mHealth applications are also critically dependent on underlying health systems and infrastructure. While mobile phones present an opportunity to extend the reach of health workers and services in over-burdened health systems in developing countries, this benefit is only possible to a certain extent (Mechael 2009; Sherry and Ratzan 2012). Effective mHealth applications will need to be

integrated with existing health systems and structures in order to achieve scale, but if the underlying infrastructure, human capacity, and material resources are lacking, the full potential of these mHealth interventions will be undermined. As Benjamin (2012) has remarked, “mobile services are primarily about linking – connecting people to information, services, and people who can help. If there are not adequate services, systems, or trained people to connect to, then mobile services are weak.” For example, applications to strengthen treatment adherence matter little when treatment is unavailable, or the drug supply is poor or inconsistent (Mechael et al. 2010, 11). Moreover, the mere presence of mobile technology introduced into health systems will not on its own generate positive outcomes—health workers need to be trained to use these applications (de Tolly 2012). Given the critical health worker shortages in Africa, human resource capacity constraints are a serious issue that must be considered in mHealth project design. In addition, several authors have cautioned that a potential unintended consequence of some mHealth applications that extend the reach of health workers, especially CHWs, is that they may bear a larger burden of servicing more clients (Déglise et al. 2012; Wessels et al. 2007). Hence staff workloads must be carefully monitored when implementing projects, so as to ensure that the extra time spent assisting more clients is actually offset by time saved due to reduced administrative burdens and other efficiencies.

### *5.2.3 Funding Challenges*

Among the most serious constraints inhibiting both the scalability and sustainability of mHealth initiatives are the lack of stable funding, and the paucity of demonstrable business models to provide for extended financial security. The pilot-based nature of mHealth intervention in developing nations, compounded by the short-term focus of most donors and international implementers, has meant that the mHealth landscape in this context

is characterized by one-time grants and project-specific or seed funding: this raises critical questions about the long-term financial sustainability of these endeavours (Iluyemi 2009). To take their pilots to scale and ensure continuing viability, mHealth organizations must either develop a revenue stream and a viable business plan that ensures projects can continue once donor grants or seed funding is exhausted, or else persuade governments to invest in programs (Foster 2010, 46). Yet until there is a sufficient body of economic analysis to determine which mHealth models not only engender positive health outcomes but are also cost-effective, developing country governments lack the information to invest their limited resources wisely, and this proliferation of financially unsustainable, small-scale, short-term projects is likely to continue (Schweitzer and Synowiec 2012).

Beyond the issue of sustainability of the broader organizations and programs, cost factors into mHealth communication design in a number of additional ways. Implementers need to evaluate both the cost to the organization, and to the prospective users of these services. The cost of purchasing and maintaining handsets remains prohibitive for the poorest people in some countries, and the cost of providing health workers with phones and/or airtime to alleviate the personal costs of using their own phones for work purposes can be prohibitive for project implementers<sup>172</sup> (Déglise et al. 2012; Kaplan 2006; Mechael 2009, 109). Organizations must also resolve the critical issue of *who* bears the cost for these services: will citizens need to pay, as we see with much commercial mHealth development in the West, or will health service providers develop strategies (such as reverse billing or using PCMs to allow users to request services for free) to provide these services at no cost to the public? As discussed above, Cell-Life has endeavoured to develop innovations that bear no cost to the user, so that these innovations may reach the poorest populations (de Tolly and

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<sup>172</sup> In South Africa (and other African countries) the costs of SMS messages can add up quickly, making it an expensive communication channel (de Tolly 2012).



Benjamin 2012). However, as a non-profit organization, Cell-Life has naturally faced the perennial funding challenges that jeopardize the long-term viability of mHealth projects, and so they need secure and sustainable funding in order to provide these services free of charge. The organization has been operating primarily on a grant basis for particular projects and research studies, funded by organizations like PEPFAR and CIDA, as well as by donations from companies like the Vodacom Foundation. Hence funding shortfalls have constrained their ability to take services to a larger scale, even though they may have the technological capacity to do so (de Tolly 2012). However, with the recent interest that the South African National Department of Health has demonstrated in mHealth in general (and in Cell-Life's innovations in particular, with partnerships like the HCT Mobile Monitoring campaign discussed above), it will be interesting to see how this materializes into longer-term funding and investment in mHealth at the national level.

#### *5.2.4 Government and Private Sector Involvement*

Direct and indirect government support impacts financial sustainability and long-term success of mHealth applications (Iluyemi 2009). Direct government investment in mHealth infrastructure and services—strengthening existing health systems—is an important aspect of helping mHealth interventions to achieve sustainability and scalability. However, government support for mHealth is not only important in terms of funding. As with eHealth initiatives more generally (Kwankam et al. 2009), a critical success factor for mHealth projects is an enabling policy environment that “encourages deployment, supports it financially, governs utilization, recognizes it as a legitimate medical service, and advances the interests of both health workers and citizens” (Mechael et al. 2010, 55). Especially in a nation like South Africa where most people are reliant on public health care systems, supportive government policy can be instrumental to a project's potential to make an

impact.<sup>173</sup> Government involvement and support at all levels—district, provincial, national, and even intergovernmental—can also help establish standardized metrics and priorities to ensure mHealth systems are fully interoperable, and integrated with existing health systems (including training procedures) (Barrington et al. 2010; Mechael et al. 2010, 69).

In addition to the important role of the government in enabling (or inhibiting) mHealth development, the very nature of the field of mobile communication means that private sector involvement is also necessarily integral to these programs' successes. Obviously, mHealth intervention, in general, is critically reliant on private telecommunication companies for cellular service provision, and the private sector has been the source of many mHealth technical innovations. Many policymakers and practitioners have advocated for public-private partnerships as the solution to successful mHealth sustainability and scalability (Barrington et al. 2010; Curioso and Mechael 2010; Kwankam et al. 2009; Schweitzer and Synowiec 2012). Indeed, in many instances, the participation of the private sector has been valuable, and corporate social responsibility has been an important impetus for funding many projects (de Tolly 2012).<sup>174</sup> However, at the same time, the profit motives of these corporations is in some respects potentially incompatible with the social objectives of mHealth for development initiatives, especially given the continued high costs of many mobile services. Mobile providers like Vodacom are now investigating mHealth from a commercial perspective, employing people to determine how they can generate profit from mHealth in South Africa (de Tolly 2012). If a viable business model can be found to benefit both citizens and the mobile providers, this can enhance the sustainability

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<sup>173</sup> Although Cell-Life has not encountered such difficulties, de Tolly (2012) noted a recent South African mHealth service that was forced to shut down as a result of policy, because it allowed doctors to offer diagnosis via mobile phone, which contravened regulation by the Health Professions Council that diagnosis be conducted face-to-face. Moreover, she also explained that South Africa lacks a single standardized electronic patient record system in the Department of Health, which will constrain future scale-up of mHealth programs in the country, at least until the government establishes a coherent policy on the issue.

<sup>174</sup> For example, Cell-life has received funding from the Vodacom Foundation, among others.

of mHealth projects. However, these market-based solutions raise concerns about equitable access to health information and services and about long-term sustainability, as well as the potential for the promotion, selection, funding, and implementation of projects which may be more profitable, but not as beneficial or transformative for health systems in developing countries.<sup>175</sup>

### 5.2.5 *Access Divides*

Even when mHealth interventions surmount technical and financial obstacles, these initiatives may still be constrained in terms of who they are actually reaching. Despite the pervasiveness of mobile phones, it must be remembered that access barriers and divides *do* persist: not everyone has a phone, and the most disadvantaged populations will likely be the ones excluded from these health communication interventions, leading to a form of “double exclusion” (de Tolly and Benjamin 2012, 317). In this sense, the extraordinarily high penetration rates of mobile telephony in developing countries may actually serve to obscure patterns of exclusion and inequality (Van Heerden et al. 2012). Especially in African contexts, these disparities in access are often heavily gendered: mobile phone ownership in sub-Saharan Africa is highly correlated with being male,<sup>176</sup> as well as being correlated to income and literacy<sup>177</sup> (Blumenstock and Eagle 2010). Such divides in meaningful access to mobile technology engender serious concerns that critical health information communicated

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<sup>175</sup> Similarly, there are numerous non-governmental development agencies and philanthropic foundations supporting mHealth projects in South Africa and in other developing countries. Their funding and in-kind contributions are critical to the financial stability and sustainability of many mHealth projects, yet here again, potentially also problematic due to possibly conflicting or incongruous objectives and priorities of the contributors and the recipients.

<sup>176</sup> A 2010 study reported that there were 300 million fewer female than male mobile subscribers, and sub-Saharan African women are 23% less likely to own a mobile phone than men (GSMA 2010). Another recent study of the mobile phone use of women living on less than US \$2 per day in low- and middle-income countries found that 74% of married women who said they did not want a mobile phone reported that this was because their husbands would not allow it, and 64% of these women who do own phones reported that a disadvantage of ownership is that it makes their husbands “suspicious” (GSMA mWomen 2012). Moreover, these women’s meaningful use of mobile phones was impeded by inadequate technical literacy skills, such as not knowing how to send an SMS (GSMA mWomen 2012).

<sup>177</sup> Indeed, literacy divides potentially exacerbate these gendered disparities, significantly impeding mHealth communication aimed at women. While women are disproportionately affected by AIDS, they also account for two thirds of illiterate adults worldwide (UNAIDS 2012).

via mHealth applications are not actually reaching everyone in the intended audience, or perhaps that those most in need are being excluded, entrenching existing knowledge gaps (Chib et al. 2012; Sherry and Ratzan 2012).

For the many text-based mHealth applications I have presented here—which are often more affordable channels of communication—barriers and limitations to access that pertain to literacy and language are especially critical. These barriers present a particular challenge for crafting health promotion and prevention messages, especially when catchment areas for mass message campaigns encompass more than one dominant language or ethnocultural context, and where levels of literacy are lower, since many of these interventions are SMS-based (Déglise et al. 2012, 15; Mechael et al. 2010, 13). With respect to literacy barriers, de Tolly (2012) posited during my interview that mHealth interventions in South Africa might be less constrained than those in other African countries, given South Africa's relatively high rates of literacy.<sup>178</sup> Moreover, she explained that any attempts to address this constraint by using non text-based applications would be greatly inhibited by cost.<sup>179</sup> Given South Africa's linguistic diversity, the choice of language for mHealth communication interventions remains especially pertinent. Perhaps surprisingly, this issue of language has not presented a significant challenge for Cell-Life. As de Tolly explained, many of their services have been offered initially in various languages, but the uptake for non-English information and communication has been very low.<sup>180</sup> However, she cautions that these language preference patterns are very region-specific, so translation is more necessary in some areas than in

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<sup>178</sup> Indeed, in Uganda, Text to Change recognized that voice applications would help reach the 48% of their target audience that was illiterate (Gurman et al. 2012).

<sup>179</sup> Cell-Life wanted to create a voice channel for one of their maternal health programs (MAMA) that would allow women to receive a voice mail reading them a message. This message would convey similar content to the SMS version, but in any language, and less constrained by the rigid length restrictions of the SMS format. However, the technology simply remains too expensive at this point for use in this context.

<sup>180</sup> For example, for Cell-Life's HIV information service on Mxit (Red), more than 80% of the usage was for the English version of the content, despite it being offered in three other South African languages, and 90-95% of the language used in the RedChatZone counselling is English (albeit the shortened Mxit version) (de Tolly 2012).

others, and this will likely be the case in many other African countries. For text-based mHealth communication applications, this translation might encounter additional challenges, particularly given the length restrictions. For example, the South African language Xhosa is on average 20% longer than English, and those extra characters can further limit the amount of information communicated in a 160 character SMS (and this translation is constrained further when dealing with non-Latin alphabets) (de Tolly and Benjamin 2012, 317). Thus, in conceptualizing, designing, and implementing mHealth interventions, we must remember that these technologies can lead to exclusion, even while opening new opportunities for communication, and hence that the implications of gender, language, literacy, socio-economic, and other divides must be taken into account.

#### *5.2.6 Privacy and Security*

These gendered and socio-cultural complexities closely relate to legal and ethical considerations pertaining to the privacy and confidentiality of mHealth applications. In general, privacy, confidentiality, and data security are critical matters pertaining to any mHealth intervention, protecting users' personal health information, keeping public health records secure, and facilitating private consultation about sensitive health issues (Mechael et al. 2010). However, these considerations are especially pertinent to HIV and AIDS mHealth applications, given the HIV-stigmatization and discrimination that still occurs in many locales, and the intimate personal and sexual nature of HIV transmission that many people may feel uncomfortable discussing openly. Mobile phones certainly offer a level of anonymity and privacy that is beneficial to health communication about these matters. Yet many researchers, practitioners, and potential end-users of mHealth services have expressed concern over the privacy and confidentiality of material communicated via mobile phone, particularly in contexts where phone sharing is a common practice (Chang et al. 2011; Chib

et al 2012; Déglise et al. 2012, 16; Gurman et al. 2012, 84; Mechael et al. 2010, 36). With HIV, a primary concern here is the potential for accidental disclosure, where an unintended recipient learns a users' HIV status as a result of intercepting a mobile communication<sup>181</sup> (de Tolly 2012). Ensuring privacy and confidentiality of mHealth communication is also especially important for vulnerable populations like sex workers or MSM (Gurman et al. 2012, 100). In this respect, social stigma can potentially compound the access barriers discussed above, creating disincentive to utilize mHealth services where one's phone access is based on shared mobile phone ownership or sporadic use of a friend or family member's phone.

### 5.2.7 *Participation*

A final critical issue to be addressed in achieving sustainable and scalable mHealth projects—as for health and development communication initiatives in general—is the level of community involvement and local knowledge incorporated into project design and implementation. As we have learnt with ICT4D and health communication in the past, transplanted interventions tend not to be as effective as those that are grounded in an intimate understanding of local needs and constraints, and embrace culturally appropriate technologies and approaches. Hence many mHealth practitioners have increasingly recognized the importance of end-user participation in project conceptualization, development, deployment, and evaluation, to ensure projects are context-specific and respond to the actual needs of the citizens and health systems they are designed to benefit (Curioso and Mechael 2010; de Tolly and Benjamin 2012; Iluyemi 2009; Neuhauser and Kreps 2010, 12). Such ideals of participatory design may not always be appropriate, as there

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<sup>181</sup> Cell-Life has actually found this to be less of a problem than they initially assumed it would be, but de Tolly (2012) suggests that might be partly due to the high rates of individual phone ownership in South Africa, and a lower level of gender disparity in ownership, whereas in other countries with lower mobile penetration and where a man might control the phone for his entire family this might present more of an issue.

are practical challenges associated with realizing the participation of target communities throughout all stages of problem identification, intervention design, message development, and project evaluation (de Tolly and Benjamin 2012, 318). However, striving to achieve deep understanding of context, environment, and culture—through formative research, analysis, and close consultation with the intended beneficiaries of mHealth communication interventions—will only strengthen these communication responses to AIDS. In addition, participation of local communities and stakeholders is also important for sustainability, supporting the move beyond donor-driven pilot projects. As noted above, one of Cell-Life’s strengths has been their intimate knowledge of local socio-cultural, political, and economic contexts. Together with their extensive collaboration with diverse local (as well as international) partners, this has likely been an important contributing factor to the success of some of their innovations, and to their longevity as an organization.

However, in addition to end-user participation in project design and deployment, another aspect of participation refers to the level of interaction and dialogicity incorporated into the actual applications themselves. As with health care generally, mHealth communication should be “personalized, predictive, preventive and participatory,” engaging people in decisions about their own health care and embracing participatory rather than unidirectional models of patient communication (van Heerden et al. 2012). Projects like Cell-Life’s MXit RedChatZone HIV counselling service enable users to become active agents in the health communication process, and genuinely help to realize the vision of interactive health communication promised by the advent of new communication technologies. Thus, mHealth communication interventions have the opportunity not only to capitalize on the mass reach of mobiles to broadcast messages to the general population, similar to more traditional health communication campaigns, but also to realize innovative alternative models,

based on engagement, empowerment, and dialogue.

Notwithstanding these seven areas of challenge, constraint, and complexity that characterize the dynamics of designing and implementing mHealth applications and potentially limit realization of scalable and sustainable interventions, mobile phones offer unprecedented new opportunities for communication in sub-Saharan Africa. mHealth promises to catalyze the increasing prevalence of mobile technology in African contexts, in order to increase the capacity of non-profit, public, and private organizations to deliver more effective and efficient health services that confront HIV and AIDS. This potential remains worthy of continued investigation and experimentation. Though the field of mHealth is in a state of relative infancy, it is clear that we have garnered sufficient evidence and insight from early experiences to at least guide future developments in more productive and cost-effective directions. The critical imperative, now, is to cautiously recognize the potential pitfalls and constraints, not to detract from mHealth's promise, but rather as a framework of necessary considerations and preconditions supporting the continued pursuit of innovative, carefully tailored, locally appropriate mHealth applications that will achieve sustained success and scalability to an extent that has not been accomplished at the time of writing.



### --- CONCLUSION ---

Throughout this thesis, I have sought to establish a theoretical framework for mHealth, informed by both ICT4D and health communication theory, in order to historicize and contextualize this burgeoning field as part of a long history of health and development initiatives. Situating mHealth as contiguous with both ICT4D and health communication projects, policies, and practice allows us to unravel the hype circulating in both mainstream and academic discourses on mHealth so as to identify the genuine potential that does exist for the use of mobile phones to have a transformative effect in HIV and AIDS intervention in sub-Saharan Africa. More specifically, this thesis has argued for the promise of mHealth to enrich health communication across the entire AIDS continuum, strengthening both the scale-up of prevention, outreach, and awareness programs and the access to treatment, care, and support for people living with HIV. The range of HIV-related mHealth applications is diverse, offering real potential to make an impact in resource-limited African settings, through more efficient and effective data collection, improved support for frontline health workers, enhanced treatment support mechanisms, and better links between citizens and the vital health information and services they need.

However, this theoretical approach to conceptualizing mHealth intervention not only deepens our understanding of the opportunities presented by mobile telephony in HIV/AIDS and development contexts, but it also affords an analytical framework within which to examine the complexities, challenges, and limitations inherent in these types of mHealth applications. Indeed, early experiences in employing mobile phones as instruments to strengthen the AIDS response have revealed critical issues and potential barriers such as sustainable funding, technology constraints, interoperability, access divides, privacy, language and literacy, underlying health infrastructure limitations, participation of end users,

and involvement of government and the private sector. Yet, in deducing more prescriptive policy-oriented conclusions or lessons about the preconditions necessary to achieve success, scalability, and sustainability, we can also use this theoretical foundation to extrapolate what the lessons of past communication-based interventions in both health and development contexts teach us about creating effective mHealth interventions to address the AIDS epidemic in sub-Saharan Africa. In other words, we have learnt so much, throughout decades of research and practice on communication for health and development, that we would be remiss not to apply those lessons to mHealth. Thus, when we are pausing to examine the research gaps on mHealth for HIV in developing countries, the barriers inhibiting the realization of mHealth's full potential in this context, and the lessons to take forward as we strive to implement this research to develop more effective and appropriate interventions, we must also consider the research gaps, barriers, and lessons that we have derived from our study of these two related fields of theory which intersect in mHealth.

To begin with, this means emphasizing the paramount importance of developing context-specific approaches to mHealth intervention, with responses grounded in careful consideration of local needs and opportunities. The ultimate efficacy and utility of health and development communication is, to a large extent, dependent upon its adaptation to local social, political, economic, and cultural contexts, and the degree to which it responds to the needs and priorities of local communities. Thus, there is a critical need to take into account the broader socio-political and communication environment—the broad forces that shape the use, meaning, and impacts of communication technologies—and select the technological tools, channels, and communicating styles that are most appropriate. Incorporating end users and beneficiary communities into project conceptualization, development, and deployment can help to achieve this context-based approach, since participatory design processes will

inspire locally tailored content, and local involvement engenders more appropriate and sustainable intervention models. Moreover, participation is critical when striving for two-way communication and interactivity, engaging people in dialogue rather than merely disseminating information to them. This is another important lesson from past ICT4D and health communication initiatives.

Importantly, embracing such context-specific and dialogue-based approaches to HIV/AIDS communication means acknowledging that the circumstances of developing mHealth programs are fundamentally different in resource-constrained developing countries than they are in the West (and, indeed, often different from one developing country to another), and hence we must not make the mistake of thinking we can merely transplant models that have proven successful in another time and place. However, project implementers must also learn from the experiences of both successful and failed mHealth interventions, striking a balancing between developing tools and content specific to local contexts and applying tools that have already been developed. This means recognizing that we cannot offer a singular ‘prescription’ for mHealth—a remedy that will work in all contexts, situations, and locales—but rather we need to develop a framework for ‘thinking through’ project design and implementation, a broad toolkit of potential opportunities and challenges to consider. Ideally, forums for knowledge-sharing and collaboration (such as the mHealth Alliance and the mHealth Working Group), will foster the collection of research, resources, software, programmatic models, and monitoring and evaluation mechanisms that can be selectively chosen and adapted to each new requirement or opportunity.

Ultimately, perhaps the most important lesson we can derive from this theoretical framework is that mobile phones are not a panacea for the challenges confronting health systems in the developing world, not the least of which being complex epidemics like HIV.

A grave risk for mHealth interventions, as for any ICT4D initiative, lies in adopting a technology-centred or technologically determinist approach, based on a technology ‘push’ rather than a needs-based ‘pull’. Despite the techno-utopian hype characterizing much mainstream discourse on mHealth, the focus should not be on the ‘m’ at all. Rather, the central question to be contemplated in designing, implementing, and evaluating mHealth interventions is whether they will ultimately improve the health of marginalized populations. Therefore, we need to remember that the spread of mobile phones, or even the use of these phones for health purposes, is not an objective *per se*; rather, mobile phones are tools that can be applied to other local, national, and regional health objectives. In this sense, mHealth should not be conceived as a stand-alone solution, but as an extension of existing health systems, with mobile phones employed as instruments integrated within interventions along the continuum of care. Such integration is also highly compatible with more holistic approaches to HIV/AIDS communication, characterized by multi-level analysis and interventions that enable broader socio-structural change. The challenge for mHealth, then, is not to design the most technologically sophisticated or impressive applications, but to devise uses of already-ubiquitous basic phones that can be genuinely transformative for health communication in resource-limited contexts. Indeed, in many respects the *technology* of mHealth is the easy part; the *implementation* is more challenging.

In this thesis, I have sought to balance theoretical analysis with the examination of relevant real-world practical experiences. The mHealth landscape has changed dramatically since I began work on this thesis, with an explosion of interest, discussion, and—most importantly for the practical facets of my work—pilot interventions. In sub-Saharan Africa, we are beginning to see governments take interest in mHealth, and successful projects are starting to be replicated and implemented at ever-larger scales. Cell-Life is taking a lead or

supporting role in many such projects in South Africa, and their experiences and insights proved quite instructive in assessing both the opportunities and challenges that characterize the African mHealth landscape. Cell-Life's work demonstrates, in practice, the diverse theoretical opportunities for mobile phones to be creatively applied and adapted to meet a broad range of HIV and AIDS intervention needs. Their work also exemplifies many of the nuances and complexities encountered in the conception, design and implementation of these interventions, and more broadly, the challenges and limitations that threaten mHealth's sustainability, scalability, and transformative potential.

Certainly, the sustainability and scalability of mHealth applications remain a prominent concern for organizations involved in the AIDS response in sub-Saharan Africa, given the significant potential for mobile phones to support and advance HIV and AIDS intervention. As discussed in Chapter Four, researchers and practitioners have increasingly been calling for more evidence—for more rigorous evaluation of mHealth projects—especially in terms of tangible cost-benefit and measurable actual health outcomes. Although these research priorities are indeed critical, we also need to examine the ways in which this exciting area of rapid development can be better informed by theory, guided by the kinds of lessons and perspectives I have enunciated here. Hence, this point of intersection between ICT4D and health communication theory should be of great interest to critical media studies scholars, as well as to health and development researchers and practitioners more generally.

The recently published *Handbook of Global Health Communication* (released in May 2012) speaks to this very point of intersection between these theoretical domains: its editors highlight a move toward theoretical convergence of the fields of health communication and communication for development and social change, in both academic debates and programmatic interventions (Waisbord and Obregon 2012). Moreover, they argue for

continued attention to critical theoretical perspectives on global health communication, with the kind of interpretive and qualitative in-depth analysis I have presented here, and which—although often overshadowed by the quantitative methodologies that dominate health science—may be better suited for analyzing social constructions of health and illness, how health inequalities are formed and maintained, and thus how they may be mitigated (Waisbord and Obregon 2012, 21). With this in mind, I propose four areas of further research: (1) more critical examination of the challenges and constraints impeding the full realization of mHealth’s potential vis-à-vis HIV/AIDS and development contexts, particularly with regards to the persistent barriers to meaningful access; (2) further investigation to address the tensions surrounding the critical dependence on the private sector and the need for more effective, sustainable collaboration and partnerships between public, private, non-profit organizations; (3) greater attention to gendered perspectives on mHealth communication, with a focus on tailoring interventions so as to explicitly address the disproportionate impacts of the HIV epidemic on African women; and (4) exploration of the potential for mHealth applications to realize the full range of alternative approaches to health communication discussed in Chapter Three, supporting the conceptual shift from health communication for behaviour change to health communication for social change.

In his 1995 speech at the ITU’s World Telecommunications Conference and Exhibition, Nelson Mandela, speaking of the promise of ICTs for developing countries, declared: “If we cannot ensure that this global revolution creates a world-wide information society in which everyone has a stake and can play a part, then it will not have been a revolution at all.” The same is true for claims of the mHealth ‘revolution’. If we can ensure these mobile technologies and applications are extended to the most vulnerable and disadvantaged citizens, if we can design mHealth interventions that foster social justice and

genuine health outcomes for the marginalized and the poor in developing nations, if we can embrace more interactive and empowering forms of health communication, catalyzing this technological potential for dialogue and participation, not just dissemination—only then may we rightfully proclaim that mHealth’s genuine ‘revolutionary’ or transformative potential for AIDS intervention in sub-Saharan African has been realized.

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## **APPENDIX A: THEORIES OF BEHAVIOUR CHANGE IN HIV PREVENTION**

Some of the most influential theories of health and human behaviour that have been applied in design, development and implementation of prevention interventions include the Health Belief Model (Becker 1974), the Theory of Reasoned Action (Fishbein and Ajzen 1975), Stages-of-Change Theory/Transtheoretical Model (Prochaska et al. 1994), Social Cognitive Theory (Bandura 1986), Diffusion of Innovations (Rogers 1962), and the AIDS Risk Reduction Model (Cantania et al. 1990).

### **1. Health Belief Model**

The Health Belief Model (HBM) has been perhaps the most well-known and widely used conceptual framework informing communication in public health for the past five decades (Janz et al. 2002, 45). It was developed in the 1950s by social psychologists in the U.S. Public Health Service to predict individual responses to preventive health services, the focus at the time being on tuberculosis screening (Janz et al. 2002, 46; McKee et al. 2008, 258). This model is a value-expectancy theory—it assumes that individual behaviour is guided by personal expectations of the consequences of adopting new practices—and thus contends that a person’s likelihood to take preventive health action can be assessed based on his or her perceptions of personal risk (both perceived susceptibility and perceived severity of a given problem or illness) and the benefits of the proposed practice, weighed against perceived costs and barriers to action (Airhihenbuwa and Obregon 2000, 7; Freimuth 1992, 100-1; Janz et al. 2002; Michal-Johnson and Bowen 1992, 154; Mimiaga et al. 2009, 207-8; Neuhauser and Kreps 2010, 10). Although the HBM considers the role of external cues that trigger action, it is primarily a rational-cognitive model, presuming an individual ‘rational’ decision-maker (Freimuth 1992, 101; McKee et al. 2008, 258). Hence, health communication strategies based on the HBM have focused in most instances on delivering rational, risk-

based messages<sup>182</sup> to individuals with the expectation that this will lead to behaviour change and adoption of healthier or preventive practices (Neuhauser and Kreps 2010, 10). However, critics have noted that such a model might be more appropriate to predict responses to one-time immunization or screening test programs than for the more complex dynamics involved in long-term changes in lifestyle behaviours, such as adopting safer sexual practices (Freimuth 1992; Janz et al. 2002, 51).

## **2. Theory of Reasoned Action**

Similar to the HBM, the Theory of Reasoned Action (TRA) identifies individual thoughts and perceptions as important determinants of behaviour, and assumes a rational decision-making process (McKee et al. 2008, 259; Michal-Johnson and Bowen 1992, 153). However, the TRA introduces a focus on the idea of behavioural ‘intent’: the theory supposes a linear progression from attitudes and beliefs about a given behaviour, influenced by subjective norms, through to action, in which an individual’s intention is the most important determinant of behaviour (Airhihenbuwa and Obregon 2000, 7; Mimiaga et al. 2009, 209; Montaña and Kasprzyk 2002). Thus, for this theory, health communicators must strive to influence individuals’ perceptions of social normative pressures—the notion that ‘significant others’ expect them to perform the recommended behaviours—in order to strengthen their motivation and commitment to changing their behaviour. This linear model has often been criticized on the grounds that intention does not always follow through to actual behaviour, and later formulations of the TRA accounted for the impact of non-volitional factors that

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<sup>182</sup> It is worth noting that while these risk-based messages are to some extent necessary to persuade people of their possible susceptibility to infection, as some acknowledgement of risk is often necessary for action (Janz et al. 2002), taken too far in relying on the use of fear to promote behaviour change, this approach can generate unintended negative consequences such as further stigmatizing or demonizing people living with HIV. Notable examples of such fear-based messages include the infamous 1987 Australian “Grim Reaper” PSA, the recent controversial “It’s Never Just HIV” PSA from the New York City Department of Health, and the particularly egregious 2009 German “AIDS is a Mass Murderer” campaign of print and television ads, which depicted graphic sexual scenes of women having supposedly unprotected sex with HIV positive men—represented as Hitler, Stalin, and Saddam Hussein. Similar French print ads in 2004 depicted HIV positive sexual partners as human-sized scorpions and tarantulas.



influence behaviour (Mimiaga et al. 2009, 209).

### **3. Stages-of-Change Theory/Transtheoretical Model**

A similarly linear approach to explaining the psychological process of behaviour change is the Transtheoretical Model (TTM), which is also sometimes referred to as the Stages-of-Change Theory. The TTM integrates principles from a number of earlier theories to identify a common set of distinct stages through which all individuals supposedly progress in the process of changing health behaviours: pre-contemplation (no thoughts of change), contemplation, preparation, action, and maintenance (Fukuda and Ebina 2011, 174; McKee et al. 2008, 259; Prochaska et al. 1994). Health communication based on the TTM would strive to address individuals according to their respective stages in the change process, matching interventions to their needs at each stage and providing the most relevant information and motivation to encourage them to advance to the next stage (McKee et al. 2008, 259). However, unlike the TRA, this model is perhaps more circular than linear, as it suggests people may return to earlier stages as a ‘relapse’ in this process of change (Mimiaga et al. 2009, 212). The TTM, though widely used, has been criticized for reducing the complexity of human behaviour to oversimplified distinct stages, rather than a broader continuum in the process of change (Mimiaga et al. 2009, 211-12).

### **4. Social Cognitive Theory**

A theory that attempts to offer a more dynamic model of human behaviour, by considering the social context alongside individual cognitive factors, is Bandura’s Social Cognitive Theory (SCT). One of the theories most frequently applied to guide the development of HIV prevention programs, the SCT focuses on the interaction of internal factors and external determinants in shaping behaviour, postulating that one’s behaviour is the result of a “reciprocal deterministic” relationship between individual factors (cognitive,

affective, and biological), behaviour, and environment (Baranowski et al. 2002; Freimuth 1992, 101; McKee 2008, 260; Mimiaga et al. 2009, 208-9). Two aspects of this theory that have been particularly instructive in the domain of HIV/AIDS communication are the concepts of “self-efficacy” and “social modeling” (Airhihenbuwa et al. 2000, 7). Self-efficacy refers to belief in one’s personal capacity to adopt a given behaviour, and maintain performance of that behaviour in the face of potential obstacles. Social modeling is based on the notion that people learn vicariously through observing and imitating others who are well-respected or seen as similar to themselves (Freimuth 1992, 101; Melkote et al. 2000, 19; Mimiaga et al. 2009, 208-9). Thus, for people to initiate and maintain a given behaviour change (such as to adopt condom use), it is critical for them to feel competent to do so, and such self-confidence may be strengthened through role-playing or by observing people similar to themselves exercising control over situations similar to those they might encounter (such as observing couples demonstrating effective negotiation of condom use prior to intercourse). Despite the consideration of environmental influences offered by SCT’s understanding of behaviour as a reciprocal process, and its emphasis on the role of social or culturally relevant behavioural role models in demonstrating behaviours, this theoretical framework offers limited attention to the broader social contexts enabling and constraining behaviour (Melkote et al. 2000, 19). SCT primarily offers an individual psychological model of behaviour change—focused on individual self-efficacy rather than collective efficacy—and hence it has been suggested that SCT may be less appropriate in more collective and communal cultural contexts (Airhihenbuwa and Obregon 2000, 7).

## **5. Diffusion of Innovations**

A second theory which starts to take into account the larger social influences on individual behaviour, and theorizes the process of behaviour change at a community or

societal level is Rogers' Diffusion of Innovations (DOI) theory. This model has been particularly influential in the dissemination of health information in development contexts—especially within the modernization paradigm discussed in Chapter Two—as it offers an explanation of the process by which members of a community accept and adopt 'innovations' such as new ideas, attitudes, technologies, or practices (Fukuda and Ebina 2011, 174; McKee et al 2008, 261-2). Rogers identified five stages through which all individuals eventually pass in the innovation adoption process: awareness, knowledge and interest, decision, trial, and adoption/rejection (McKee et al 2008, 262; Waisbord 2001, 4). The diffusion of innovations theory has been most influential on HIV/AIDS communication with respect to two of its principles in particular: Rogers' emphasis on communication channels—especially mass media—as crucial vehicles of diffusion, and on the influence of 'opinion leaders' in shaping individual attitudes, beliefs, and behaviours (Airhihenbuwa and Obregon 2000, 7-8; Freimuth 1992, 102-3). From this perspective, health communicators might understand that a new behaviour such as condom use might first be made known to the people in a given population through media campaigns that create awareness, provide information, and stimulate interest in this new 'innovation,' but that that these media messages alone will not stimulate behaviour change. Campaign planners must ensure that important cultural leaders in the community also embrace and publicly endorse this new behaviour, reinforcing positive perceptions of condom use and motivating individuals to decide to try using condoms themselves. Although this model has been criticized for its linearity and pro-innovation bias, it is worth noting that involving local opinion leaders in communication planning can create a platform for developing more culturally appropriate strategies (Airhihenbuwa and Obregon 2000, 8; Freimuth 1992, 103).

## **6. AIDS Risk Reduction Model**

The final theory of behaviour change that has been commonly used to interpret individual AIDS-related health attitudes and behaviour—and, in fact, the only model specifically formulated for AIDS—is the AIDS Risk Reduction Model (ARRM), developed in 1990 (UNAIDS 1999, 6, 8). Attempting to understand why individuals fail to make changes in behaviour, the ARRM combines elements of other dominant models (particularly the HBM, SCT, and diffusion of innovations), and posits that behaviour change is a process consisting of three stages—behaviour labeling, commitment to change, and enactment—through which individuals pass in order to change sexual behaviour related to HIV transmission (Cantania et al. 1990; Melkote et al. 2000, 18; Mimiaga et al. 2009, 213). Individuals must first recognize and label their current behaviours as putting them at risk for contracting HIV, then make a commitment to reduce those high risk activities and increase behaviours associated with lower risk, and finally develop strategies and take action to achieve these goals. Hence, interventions based on the ARRM have focused on promoting individual risk assessment; influencing desire for, and commitment to, risk-reduction behaviour (through perceptions of severity of HIV risk, self-efficacy for changing behaviours, and enjoyment associated with change); and assisting individuals with the process of enactment through the provision of material and social support, such as access to condoms and counselling (Mimiaga et al. 2009, 213).

## **APPENDIX B: NON-COMMUNICATION-BASED MHEALTH APPLICATIONS FOR AIDS INTERVENTION**

Chapter Four describes a category of *health communication* applications of mobile phones in HIV and AIDS intervention that connect citizens with health information and services. There are three other, often more technical categories of mHealth applications that bear upon HIV and AIDS intervention in sub-Saharan Africa: (1) enabling data collection and disease surveillance; (2) supporting frontline health workers; and (3) enhancing treatment and care. Although they are not directly germane to the focus of my thesis, these other application categories nevertheless present equally important opportunities to strengthen health systems in developing countries. They offer the potential to improve healthcare efficiencies, overcome geographic barriers, and enhance access to information, training and support for health workers and their patients. I will briefly describe and provide examples of these three categories here, in order to provide a more complete view of the broader prospects for mHealth in HIV/AIDS responses in developing countries.

### **1. Data Collection and Disease Surveillance**

One of the most frequently cited mHealth interventions is the use of mobile phones to assist in remote data collection and health information management—vital components of public health programs. This type of application is a more technical solution aimed at achieving efficiency gains, particularly in remote or resource-limited settings where time-consuming paper-based information systems predominate (Sørensen et al. 2008; Mechaël et al. 2010, 23). Mobile devices (including both PDAs and mobile phones of varying levels of sophistication) can facilitate a much more rapid process of data gathering and analysis, with applications designed to allow dispersed health workers to collect information on their phones and transmit it to central health facilities in real-time. The resulting evaluation and

analysis of this information can occur immediately, often aided by a computer program, affording more rapid responses for prevention and treatment to reach those in need. In theory, such applications improve both the efficiency and accuracy of data collection and analysis, meaning that more timely and accurate health data is available to enable health workers and policymakers to make better-informed decisions, from monitoring drug supplies to responding more quickly to emerging epidemics (Leach-Lemens 2009). This has a significant bearing on HIV work both in terms of epidemic surveillance, including monitoring HIV incidence in high-risk populations, and in terms of managing treatment programs. One of the challenges associated with HIV care is that antiretroviral treatment management requires ongoing monitoring and evaluation, and access to accurate and up-to-date information at the national, provincial, and district planning levels (Sørensen et al. 2008). Mobile systems are perceived to have a significant role to play in improving access to such data.

One prominent example of a data-oriented mHealth program is EpiSurveyor, an open-source application developed by the non-profit software provider DataDyne.org. EpiSurveyor is downloadable mobile software that allows users to create and fill in forms for collecting medical data, which can be sent to a central computer to be analyzed in real time—a cheap, fully adaptable solution to improve data collection accuracy and efficiency. It is currently being used by organizations such as the World Bank, WHO, CDC, USAID, UNICEF, and various ministries of health, for projects implemented in over 170 countries, including wide deployment across Africa (EpiSurveyor.org; Mechaël et al. 2010, 25). A potential drawback of the system is that EpiSurveyor relies on the Internet to create forms and receive and analyze the information collected, and requires more sophisticated phone models that may not be affordable or widely available in resource-constrained settings. Indeed, this is true of much of the work that has been done in developing and implementing mHealth data

collection applications: they are often based on PDAs and, more recently, smartphones, with many interventions also using an Internet connection to transmit data (Mechael et al. 2010).

However, a number of applications have been designed for the most basic handsets as well, and have experimented with different methods of data exchange. In Rwanda, a large PEPFAR-supported public-private partnership<sup>183</sup> called Phones for Health is working with the government's Ministry of Health to build upon the existing TRACnet program, established in 2005, which manages Rwanda's HIV/AIDS program through a comprehensive system to collect, store, retrieve, and disseminate vital information between central clinics and health workers in local communities (Leach-Lemens 2009, 6; Vital Wave 2009, 49). The program uses simple Motorola handsets and a downloadable application, and data is transferred via either a packet-based mobile connection (GPRS) or an SMS data channel.<sup>184</sup> In a country where countless hills and muddy roads cripple the transfer of information from rural villages to health centres in the rainy season, sometimes taking weeks, the capacity for constant communication and information-sharing with health workers in these remote areas presents a simple but effective solution (Leach-Lemens 2009, 6). TRACnet was praised as the first African national-scale real-time HIV/AIDS information management system, and the Phones for Health partnership is expanding to nine other African nations (Leach-Lemens 2009, 6). Although most applications in this category are text-based, several studies have experimented with leveraging other functionalities of mobile phones for enhanced collection of health data, including the use of voice-based reporting and GPS location mapping (Mechael et al. 2010, 26-27).

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<sup>183</sup> Other partners include the GSMA Development Fund, MTN, Motorola, Accenture Development Partnerships, and Voxiva (Leach-Lemens 2009, 6).

<sup>184</sup> Similarly, another pilot project successfully demonstrated the effectiveness and practicality of using a simple SMS-based system, compatible with any mobile phone network or handset, to collect data and monitor stock levels of anti-malarial medicines in rural districts in Tanzania (Barrington et al. 2010). Such a system could readily be adapted to ARV stock monitoring systems.

For resource-limited health ministries and non-profit organizations, especially those serving rural populations, the potential to lesson geographic constraints while improving data quality and lowering costs is a very appealing promise. Indeed, integrating mobile phones into these information systems presents a significant opportunity to improve data gathering. However, while a number of these data and surveillance applications present significant potential and have demonstrated evidence of efficiency gains, including cost- and time-savings and improved accuracy rates over traditional paper-based data collection processes, little attention has been paid to the impacts of these applications on health outcomes or health systems strengthening (Mechael et al. 2010, 24). More research is needed to investigate these outcomes, as well as the potential benefits extending beyond disease-specific applications that merely replace paper methods without more extensive integration into other components of the health system (Mechael et al. 2010).

## **2. Supporting Frontline Health Workers**

Given the crucial shortage of health professionals facing sub-Saharan Africa, and the frequent reliance on Community Health Workers (CHWs) to provide essential health services, a number of mHealth applications have targeted these over-burdened frontline health workers in order to help extend their reach and caregiving capacities. Such applications aim to improve access to pertinent information and enhance channels of communication so as to improve diagnosis, treatment, quality of care, and, ultimately, overall health outcomes. These applications primarily serve to overcome the challenge of monitoring and communicating with a large number of geographically distributed frontline health workers, and thus focus on a number of different areas of their work, including: facilitating communication between clinics and CHWs (and their patients) to improve the efficiency and quality of patient care; improving access to training and reference materials for both health professionals and



CHWs; providing point-of-care decision and diagnostic support tools; and empowering CHWs with remote support, supervision, and guidance, allowing them to deal with a broader scope of health issues (DeRenzi et al. 2011; Vital Wave 2009). Fast, reliable, and inexpensive communication between frontline health workers and regional health facilities also enables more rapid emergency medical response, allowing help (in the form of health professionals, drugs, and other medical supplies) to be dispatched promptly and emergency cases to be managed more immediately<sup>185</sup> (Lemay et al. 2012; Mechael et al. 2010, 31). Moreover, many of these applications can be closely linked with the mobile data collection systems discussed above, allowing frontline health workers not only to access information and support materials, but also in turn to report data back to health centres and build electronic medical records.<sup>186</sup>

One of the main themes of this stream of mHealth applications is extending health information systems and communication networks to include CHWs working in remote areas, and not just professionally trained clinicians, resulting in collaborative support systems that overcome geographic barriers to provide more timely and efficient care (Mechael et al. 2010, 12). One of the earliest large-scale implementations of such a system in sub-Saharan Africa was the Uganda Health Information Network (UHIN), which was launched in 2003 by SATELLIFE, Canada's IDRC, and local partners. UHIN distributed PDAs to remote health workers for storing and transmitting health information, allowing these workers both to access relevant information (like a virtual medical library) and to report data collected in the field (Haider et al. 2009; SATELLIFE 2011). The project demonstrated cost-effectiveness,

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<sup>185</sup> Indeed, access to a phone (mobile or fixed) can be potentially life-saving for any citizen, affording the capacity to call for help in an emergency.

<sup>186</sup> Mechael and colleagues (2010) suggest that more research is needed in this area, to identify the effects on quality of care that result from deploying systems that integrate point-of-care support tools with data collection/surveillance.

improved data quality, and minimized delays associated with travel, and it has been replicated in other African nations (Leach-Lemens 2009; SATELLIFE 2011).

Access to updated information on treatment protocols and drug information can be especially beneficial for treating HIV, with its complex care and drug requirements. To address this need, software company Dimagi, Inc. (along with the Harvard School of Public Health) developed an HIV Mobile Decision Support software program that is being piloted in South Africa to help health workers assess patients and determine their HIV treatment needs, through the use of a mobile-based survey guiding them through triage and diagnosis processes (although it only runs on a Windows smartphone) (Dimagi n.d.). A similar point-of-care system to assist frontline health care providers with HIV medication dosing has been developed for the Android mobile platform (Sadasivam et al. 2012). The range of mobile diagnostic support tools available also includes portable diagnostic devices, such as the Cellscope (a device attached to a mobile phone that can analyze red and white blood cells like a microscope) and the Cellophone (an optical imaging platform that allows users to analyze bodily fluids within a mobile phone through the LUCAS shadow imaging technology, with no special lens attachments) (Leach-Lemens 2009, 6).

Until relatively recently, many of these applications supporting frontline health workers have only been documented in gray literature, and academic articles have focused primarily on cost savings and data reliability (Mechael et al. 2010, 13). However, a number of studies exploring this area of mHealth have been published over the past two years, including some that report on outcomes relating to improved quality of care. For example, a Kenyan trial demonstrated the effectiveness of a text messaging program to improve health workers' case management practices, including adherence to national guidelines for malaria treatment (Zurovac et al. 2011). A project in Uganda demonstrated that mobile phones can be

used as a cost-effective platform for ongoing health worker learning, reinforcing face-to-face training in clinical protocols and thereby improving the quality of care provided<sup>187</sup> (Riley and BonTempo 2011). In Zambia, Project Mwana used mobile phones and SMS communication to overcome logistical and geographic barriers and increase the speed and efficiency of early infant diagnosis of HIV. Whereas the previous system depended on paper-based records and courier delivery, the integration of mobile phones made possible the rapid communication of blood test results from regional laboratories to the point-of-care health facility<sup>188</sup> (Seidenberg et al. 20120). Such an SMS-based system for notification of test results has potential for application to other HIV testing scenarios, particularly in rural areas.

In Malawi, a country with one of the most severe health worker shortages on the African continent, several mHealth applications have been deployed to help address this constraint. One program, based at the rural St. Gabriel's Hospital in Namitete, used the FrontlineSMS:Medic<sup>189</sup> (now called Medic Mobile) platform to connect CHWs in district villages with the hospital, supporting them in patient referrals, adherence reporting, appointment reminders, physician queries, drug information and supply management, and emergency care. The hospital serves a catchment area of primarily rural subsistence farmers spread over an area 100 miles in radius, but the programs eased this geographic barrier and effectively supported the hospital's ART, TB, PMTCT, and home-based care programs, producing significant cost and time savings and increasing the number of patients served (Mahmud et al. 2010). A similar initiative was recently established in the country's Salima

<sup>187</sup> Another pilot used smart phones for HIV/AIDS-related training for healthcare workers in resource-limited setting in Peru, although the project's impact was limited by software interoperability issues and prohibitive investment costs for the high-end phones (Zolfo et al. 2010).

<sup>188</sup> The authors suggested that the system could be further improved by extending this SMS communication chain to reach caregivers directly to notify them that their test results have been received, or to communicate this information via a local CHW in the area if the caregivers do not have access to a mobile phone (Seidenberg et al. 2012).

<sup>189</sup> FrontlineSMS is a free, open-source software platform that enables users to send, receive, and manage large-scale SMS communication (FrontlineSMS.com). Designed for developing country contexts, it has minimal infrastructure requirements—only a basic computer connected to a modem or a mobile phone—and offers diverse functionalities, from mass-messaging to auto-reply. Medic Mobile is a non-profit organization that develops and extends existing open-source tools like FrontlineSMS to create software specifically designed for health care purposes.

and Nkhotakota districts, demonstrating efficiencies, cost reductions, and improved service quality in comparison to a control district. It also improved the social status of CHWs in the intervention group, who felt more empowered in their work and received greater recognition from their clients and communities (Lemay et al. 2012). A study in Uganda also found a positive impact on CHW morale as a result of an mHealth intervention for peer health workers (CHWs that are living with HIV themselves) engaged in AIDS care (Chang et al. 2011). Although the Ugandan study found no significant difference in patient risk of virologic failure after 26 months, qualitative analysis identified improvements in patient care, logistics, and broad support for the intervention from patients, clinic staff, and PHWs. While this initiative used the phones for both voice and SMS channels of communication, the primary benefit of the technology seemed to lie in the capacity to simply make and receive voice calls (Chang et al. 2011, 1782). This speaks to the fact that, especially in developing country contexts, the simplest technological innovations may in fact generate the most positive outcomes—another reason why programs developed for high-income countries are not necessarily transferable. While these mHealth applications all take slightly different approaches to supporting frontline health workers, many of them are notable for their integration with existing health systems, strengthening communications and relationships between professional and informal health workers and their patients. In this respect, projects that enhance and extend pre-existing health services may be more sustainable than those introduced as standalone projects.

### **3. Enhancing Treatment and Care**

Perhaps the most extensive research, project deployment, and evidence documented in mHealth literature is in the area of applications that support treatment through promoting medication adherence and remote monitoring (Mechael et al. 2010, 12). This area of

intervention is perceived to be particularly promising given the possibility for reducing hospital or clinic visits (with associated time and travel cost savings) and improving efficacy of treatment. Although much of the mHealth literature on treatment adherence and remote patient monitoring has focused on the management of chronic disease in high-income countries, an increasing number of studies have addressed the use of mobile phones for infectious disease drug adherence in developing countries (Mechael et al. 2010, 15).

This area of mHealth application is especially compelling for HIV care interventions, given the critical importance of ART adherence for both individual therapeutic benefits and broader prevention strategies. As access to life-saving antiretroviral drugs has increased dramatically in developing countries,<sup>190</sup> so too has the need for interventions to support and enhance ART adherence. The advent of HAART has dramatically improved the lives of people living with HIV, helping them to feel better, live longer, and slow the progression of the disease. However, the life-extending benefits of ART are only achieved through sustained high levels of adherence, which means patients must take daily or twice-daily medication for the rest of their lives, typically with a minimum of 95% regimen adherence (Bärnighausen et al. 2011; Lester et al. 2010; Wessels et al. 2007). Yet many people find it difficult to consistently adhere to such a lifelong treatment regimen, due to side effects, lack of motivation and support, or other barriers, and hence long-term retention rates of ART programs are relatively low, jeopardizing these programs' success (Bärnighausen et al. 2011; Mills 2006; UNAIDS 2010, 100; WHO 2011c). Incomplete adherence represents a leading cause of HIV treatment failure (Conway 2007; Hogg et al. 2002), and yet only 60% of people who start ART in sub-Saharan Africa continue after two years (Rosen et al. 2007).

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<sup>190</sup> By the end of 2010, more than 6.5 million people in low- and middle-income countries were receiving ART, up from just 400,000 in 2003, and representing coverage of 47% of those in need (WHO 2011c, 89-90).

Moreover, high ART adherence is not only crucial for patients' own health outcomes and survival. Missed medication also results in increased viral loads, which impacts prevention and epidemic control efforts, since achieving suppressed viral loads has proven highly effective in diminishing the likelihood of HIV transmission<sup>191</sup> (Bärnighausen et al. 2011; Cohen et al. 2011). Another serious risk associated with prolonged treatment interruptions or stoppage is the opportunity for the virus to mutate against the drug regimen, with patients developing drug-resistant forms of the virus (Gardner et al. 2009; Wessels et al. 2007, 609; WHO 2011c, 106-7). This results in severe increases to health care costs associated with HIV treatment, since drug resistance necessitates expensive<sup>192</sup> and complicated second-line treatment regimens (Lester et al. 2010; WHO 2011d). It also creates the possibility for transmission of HIV drug resistance, presenting a serious public health concern. Thus, there is a paramount need for cost-effective mechanisms to support and monitor adherence to HAART, as well as to reduce loss to follow-up in PMTCT programs,<sup>193</sup> in order to realize both the preventive and therapeutic benefits of treatment (Thirumurthy and Lester 2012). This central importance of adherence is also true to TB treatment, as patients are inclined to stop taking their medication once their symptoms are alleviated and they feel healthy again.<sup>194</sup> In addition, HIV and TB co-infection presents a serious challenge: one third of people living with HIV also have a latent TB infection, HIV positive status is the greatest

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<sup>191</sup> This is the rationale behind recent promotion of 'treatment-as-prevention' approaches to HIV prevention.

<sup>192</sup> In 2010, second-line treatment regimens in low- and middle-income countries were at least six times more expensive than first-line treatment—a severe financial burden for already constrained health systems (WHO 2011d).

<sup>193</sup> Although there has been little mHealth research or experimentation directly focused on PMTCT programs, results from other areas of mHealth intervention indicate that mobile phone technology presents significant potential for this crucial area of HIV prevention, particularly in reducing the loss to follow-up that occurs at each stage of the cascade of basic PMTCT services (from antenatal visits to VCT to early infant diagnosis), all of which are critical for keeping children HIV-free (Philbrick 2012; Thirumurthy and Lester 2012, 391). Cell-Life currently has a study underway in this area, as described in Chapter Five of this thesis.

<sup>194</sup> Although TB is fully curable, these treatment interruptions and stoppages have led to an increased incidence of multi-drug-resistant TB (MDR-TB), resistant to the two most powerful first-line TB drugs, and to an even more frightening new form of extensively drug-resistant TB (XDR-TB), which is also resistant to powerful second-line drugs (UNAIDS 2011). Nearly 10% of TB cases in South Africa present MDR-TB (Streicher et al. 2012). The success of mHealth interventions to improve TB treatment adherence is highly pertinent to HIV intervention for their potential applicability, given the shared characteristics of these two diseases.

risk factor for developing TB disease, and sub-Saharan Africa accounts for 82% of global cases of co-infection (WHO 2011c). Hence, they must be addressed jointly any health sector response, integrating TB and HIV services, where possible, in order to “prevent TB- and HIV-related transmission, morbidity, and mortality” (WHO 2011c, 117).

In light of the central importance of adherence to HIV treatment efficacy and public health strategy, applications that support and enhance treatment have been a logical and popular area of mHealth intervention. Even before advent of mobile, telephone communication was one of the simplest and most cost-effective strategies for keeping patients engaged in health care and improving their adherence to long-term medication regimens (Haynes et al. 1996). Thus many studies have designed interventions that use mobiles to enhance adherence to ART, primarily using SMS technology for sending reminders to take drugs and attend appointments<sup>195</sup> (Mechael et al. 2010). For example, two recent RCTs have been undertaken in Kenya, investigating the potential for text message interventions to improve adherence to ART.<sup>196</sup> One study, conducted by WelTel Kenya, involved clinic nurses sending weekly SMS messages to patients, and required them to respond within 48 hours. Patients who received this SMS support intervention demonstrated significantly improved ART adherence and successful viral load suppression after one year, compared to the individuals in the control group who did not receive any messages (Lester et al. 2010). The second study compared the impacts of one-way SMS reminders that were either short or long, and sent at either daily or weekly intervals. This study also demonstrated the efficacy of text messages to improve ART adherence, and interestingly found that the

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<sup>195</sup> A recent meta-analysis and systematic review confirmed the substantial impact that SMS reminders have on increasing likelihood of clinic appointment attendance (Guy et al. 2012). An example of such a program is the free, open-source TxtAlert service developed in South Africa in 2007 by the Praekelt Foundation. The service sends ART patients reminders of upcoming clinic appointments one day and two weeks in advance, and allows them to reschedule if necessary, via free “Please Call Me” (PCM) messages (Neethling 2011). This form of communication between patients and health service providers is inexpensive, and has reduced the rate of treatment default to less than 4% in one trial in a South African clinic (Mapham 2008). Praekelt is currently expanding this service to support TB and PMTCT programs as well (Neethling 2011).

<sup>196</sup> A similar RCT is underway in Cameroon (Mbuagbaw et al. 2011).

weekly messages produced significantly higher adherence than the daily messages, whose recipients showed no better adherence than individuals in the control group receiving standard care (Pop-Eleches et al. 2011). Both studies proved cost-effective, given the marginal cost of text messages in Kenya, but the intriguing results of the second study suggest that there were supportive factors intrinsic to this communication intervention that extended beyond merely functioning as reminders<sup>197</sup> (Thirumurthy and Lester 2012).

A fundamental challenge associated with this type of mHealth intervention lies in carefully crafting messages that are empowering, motivational, context-appropriate, sensitive, and potentially coded to protect recipients' privacy (i.e., to prevent accidental disclosure if someone else sees the message) (Mechael et al. 2010, 17). Based on their work in the United States, Coomes et al. (2012) suggest that effective SMS interventions to promote ART adherence and improve clinical outcomes for people living with HIV requires extending message content beyond simple reminders, to impact other mutually reinforcing behaviours and factors. Examples of such extensions include the promotion of general health and well-being, persuasion to reduce risk behaviours, and attempts to increase patient involvement and social support. Treatment literacy is also an important factor here, as self-management and adherence programs are most effective when combined with disease- and treatment-specific education, and higher levels of health literacy have been demonstrated to be directly associated with greater HIV treatment adherence (Kalichman et al. 2008; Mapham 2008). The importance of education and social support in enhancing the efficacy of treatment and care should not be undervalued. Understanding treatment regimens can help patients to feel empowered in relation to treatment decisions, and this has been shown to result in higher

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<sup>197</sup> This social support aspect was also demonstrated by a pilot project in Mexico which created a virtual support group by providing ART patients with mobile phones, unlimited text messages, and a network to communicate with each other. The project was successful, with positive social outcomes reported by participants, but the high costs of the project meant it was unable to continue beyond three months (Mapham 2008, 14).



rates of adherence and more positive attitudes towards ART (Webb et al. 2001). The recognized importance of patient empowerment is also reflected in the preference for the term ‘adherence’ over ‘compliance’: whereas compliance implies a restricted biomedical-centred understanding of treatment, adherence reflects a more patient-centred model that acknowledges a patient’s autonomy and choice in treatment practices (Lutfey and Wishner 1999; Williams and Friedland 1997).

In a different approach, some projects have taken mHealth intervention beyond motivational support messages and reminders, and have actually integrated monitoring technology into the intervention.<sup>198</sup> A notable example is the SIMpill solution, an electronic TB treatment adherence support technology that was piloted in South Africa, and could be adapted to HIV treatment. SIMpill equips a pill bottle with a SIM card, which automatically transmits a message to the patient’s designated health provider when the bottle is opened, and a caregiver is notified by SMS if the patient does not take the medication within a prescribed timeframe (Vital Wave 2009, 54). The South African trial demonstrated significantly improved TB outcomes (a 94% compliance rate and 92% cure rate, compared to the typical 22-60% adherence without the system), and lowered the average cost per patient by mitigating the higher costs associated with treatment failure (Broomhead and Mars 2012; SIMpill 2008; Vital Wave 2009, 54). While such surveillance may be effective, and indeed a

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<sup>198</sup> These remote monitoring technologies constitute a large part of the mHealth technological innovation and marketing hype, particularly in the West, with development of pervasive and wearable sensor technologies integrated with a wireless network, often controlled by a mobile phone application. These technologies extend telemedicine by actually recording and processing biomedical signals and communicating this information in real-time to a physician, who can monitor, diagnose, and treat illnesses remotely (Istepanian et al. 2004). One such technology that received considerable hype at the December 2011 mHealth Summit in Washington, D.C. was an “electric band-aid,” which is an adhesive strip capable of transmitting the wearer’s health status (monitoring hydration, breathing, temperature, and even sending an EKG) to a mobile phone via Bluetooth connection, all for a manufacturing cost of approximately US \$1 (Bose 2012). Such advanced technologies create new opportunities to support the management of chronic diseases or medical events, such as monitoring women during pregnancy.

common protocol with TB treatment,<sup>199</sup> it may beget privacy concerns, and the proprietary nature of the software limits its potential application in severely resource-limited settings.

While these technological innovations no doubt simplify remote monitoring practices, generating time and cost savings for the health sector, in order to truly enhance treatment and care, they will likely need to be implemented alongside more supportive and empowering communication.

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<sup>199</sup> Directly Observed Treatment (DOT) is a common practice to improve the efficacy of TB treatment. A recent proof-of-concept pilot in Kenya demonstrated the technical feasibility of Mobile Direct Observation of Treatment (MDOT) using mobile phone video capture and transmission (Hoffman et al. 2010).

## APPENDIX C: ETHICS APPROVAL



*Office of the Dean*

### Ethical Review of Research Involving Human Subjects

All non-medical research involving human subjects at the University of Western Ontario is carried out in compliance with the Social Sciences and Humanities Research Council Guidelines (2010). The Faculty of Information Media Studies (FIMS) Research Committee has the mandate to review minimal-risk FIMS research proposals for adherence to these guidelines.

#### 2010 – 2011 FIMS Research Committee Membership

- |                     |                         |
|---------------------|-------------------------|
| 1. J. Burkell (alt) | 6. P. McKenzie (Chair)* |
| 2. G. Campbell      | 7. D. Neal              |
| 3. C. Farber        | 8. K. Sedig (alt)       |
| 4. H. Hill          | 9. C. Whippey           |
| 5. V. Manzerolle    | 10. L. Xiao*            |

Research Committee member(s) marked with \* have examined the research project **FIMS 2011-005** with two revisions (FIMS 2011-005-R2 and -R3) entitled:

**An examination of the promise of mobile phones for HIV/AIDS intervention in sub-Saharan Africa**

as submitted by: Sandra Smeltzer (Principal Investigator / Associate Professor, FIMS)  
Trisha Phippard (Co-Investigator / MA student, FIMS)

and consider it to be acceptable on ethical grounds for research involving human subjects under the conditions of the University's Policy on Research Involving Human Subjects. Approval is given for the period **25 February 2011 to 30 June 2012**.

Approval Dates: Original: 25 February 2011. R2 20 December 2011, R3 17 May 2012

Pamela McKenzie, Assistant Dean (Research)  
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